

## V. Specific Population Findings

Data on specific sub-populations of persons living with HIV/AIDS are drawn from several sources. Epidemiologic data and summaries are excerpted from HIV/AIDS Epidemiology Profile for Community Planning – June 2001, published by the HIV/AIDS Epidemiology Program of Public Health – Seattle & King County. All other information is derived from data from the 2001 consumer surveys, provider interviews, and focus groups. (See Section III, Methods) Quotes from persons living with HIV/AIDS have been excerpted from focus group transcripts and narrative sections of the consumer survey and are italicized in this report.

Within each sub-population, reports are organized as follows:

- 1. Epidemiologic Profile:** A summary of the population-specific data regarding AIDS case status and trends, population size, seroprevalence estimates and subgroup highlights (where appropriate).
- 2. Service Trends:** Patterns in overall service utilization, including demographic changes and population-specific needs as identified by consumers and providers.
- 3. Service Priorities:** Services that have been identified as priorities for the target population, by consumers themselves and/or by providers with expertise and experience in working with the population. The top ten priorities per sub-population from the consumer survey are listed.
- 4. Service Gaps:** Services that consumers and/or providers have identified as deficient, either because the service is not available, not accessible, or is not delivered in a manner consistent with sub-population needs. The top ten service gaps per sub-population from the consumer survey are listed.
- 5. Access Barriers:** Factors that have been identified by consumers and providers which impede service utilization by the population, including systemic barriers and population-specific attitudes and behaviors. The top five access barriers per sub-population from the consumer survey are listed. Suggestions for overcoming access barriers are also included.

**(NOTE: All results noted as statistically significant were tested at the  $p < .05$  level.)**

## A. Men who have Sex with Men

*“Insurance keeps covering less, and a lot of meds for side effects are now over the counter. Co-pays which seem small add up too quickly when you have a chronic condition. I could get more assistance if I went onto disability. It seems to be an all-or-nothing approach that works against people who are struggling to work and only need partial assistance.” (White MSM PLWH)*

### 1. Epidemiologic Profile

Men who have sex with men (MSM) were the earliest group affected by HIV/AIDS in King County and continue to bear the largest burden of AIDS, HIV infection, and risk of infection. Of persons living with AIDS in King County, 71% are MSM and an additional 10% are MSM who are also injection drug users (MSM/IDU).

Status and trends in AIDS cases: Although MSM are still the largest subgroup with AIDS in King County, AIDS case report data show a trend towards declining annual AIDS diagnoses in MSM beginning in 1994. The proportion of AIDS cases that are among MSM who do not inject drugs has decreased from 82% in 1982-85 to 62% in 1999-2000. The proportion of cases who are MSM drug injectors has remained at about 10% (varying from 7% to 12%).

Compared to AIDS cases, data on newly diagnosed HIV cases indicate an even lower proportion of MSM and a higher proportion of other exposure categories. Of 310 newly diagnosed HIV cases reported from 9/99 through 3/01, 61% were MSM, 8% were MSM/IDU and 31% had other or unknown risks.

Population sizes: Based on data from a variety of sources, Public Health – Seattle & King County estimates that MSM number between 32,000 and 53,000 in King County, including approximately 2,500-3,800 MSM drug injectors. HIV seropositive MSM are estimated to number 4,800-7,200, including 600-900 HIV-infected MSM drug injectors.

HIV seroprevalence: Depending on the site or population of MSM and the year of the survey, local HIV seroprevalence studies indicate that between 2.5% and 36% of MSM test HIV positive. Unlinked, anonymous HIV surveys conducted during 1998-99 at Harborview’s STD Clinic revealed that 8.6% of 488 MSM tested HIV+ positive. In the same STD Clinic survey, trend analysis showed that HIV prevalence decreased from 36% for all MSM in 1988-89 to 5% in 1996-97, but rose again to 11% in 1999. The increase observed in 1999 is statistically significant and may be a reflection of a possible upsurge in HIV transmission.

### Subgroup highlights:

MSM of color: Most men of color currently living with AIDS reported male-male sex with or without IDU as a risk factor for HIV (69%). However, this proportion is lower than among white men living with AIDS (92% reporting male-male sex). In general, persons of color have a higher prevalence of HIV and AIDS than whites, but this is not necessarily the case for MSM.

MSM Injection Drug Users (MSM/IDU): Amphetamine use was reported by 40% of MSM drug injectors, in comparison to 4% of non-MSM drug injectors in unlinked seroprevalence studies at King County drug treatment centers from 1988 through 1997. In this study, the seroprevalence of HIV was 47% in MSM whose usual injection drug was methamphetamine, compared to 14% of MSM who primarily injected other drugs.

## **2. Service Trends**

As in previous years, providers of services to MSM report that the large majority of their clients are white (ranging from 80%-90%, depending on the provider). Providers reported a slight increase in gay men of color, mostly among Hispanic MSM. Providers also noted that they are seeing younger MSM clients, especially those in their 20's. They are also seeing an increase in newly-diagnosed MSM clients over the age of 40, and more clients ages 50 and older as increasing numbers of PLWH are living longer due to HAART therapy.

Increasing numbers of MSM clients are living in South and East King County, as well as clients who travel to Seattle for care from across the state. Although a higher percentage of non-Seattle respondents on the consumer survey are non-MSM, the percent of consumers with zip codes outside Seattle who reported MSM activity has increased since 1999. Providers also reported a slight increase in homeless and formerly homeless MSM clients since the last assessment was completed in 1999.

As first identified in 1997, providers continue to see increasing numbers of MSM clients presenting with histories of mental illness and chemical dependency. In particular, providers noted a high incidence of depression in their MSM clients. In many of these cases, providers identified situational depression among the growing number of clients who thought that they were dying and are now living longer than anticipated. Providers also noted that more clients are presenting with anger management issues that impact the clients' ability to interact appropriately with providers. A increasing percentage of MSM PLWH are presenting with more severe mental health diagnoses which impact their daily living, such as psychoses and personality disorders. Thirty-one percent of overall MSM respondents to the consumer survey reported having been diagnosed with a mental illness, higher than the 26% of non-MSM PLWH survey respondents who reported having been diagnosed with mental illness.

Providers report that a growing percent of their MSM clients are current or former substance users. The "drug of choice" for many of these men is crystal methamphetamine, particularly among white MSM. Smaller numbers are also reported to be using cocaine. Use of alcohol and recreational drugs, such as stimulants and non-medical marijuana, is reported as being widespread. Providers whose caseload is primarily composed of MSM/IDU report an increase in multi-drug use among their clients.

Consistent with provider reports, white MSM respondents on the 2001 consumer survey are more likely to self-report as having been diagnosed with mental illness than MSM of color populations (33% versus 26%). White MSM are also more than three times less likely to have been homeless during the previous year (6% of white MSM versus 20% of MSM of color) and almost half as likely to have been in jail or prison (5% versus 9%).

MSM survey respondents reported several significant differences in disease status and progression than was reported among other PLWH. MSM were more likely than other consumers to have received an AIDS diagnosis (56% versus 46%). MSM were significantly more likely than other consumers to know their T-cell counts (92% versus 76%) as well as their viral loads (91% versus 71%). Among consumers who were aware of these respective health markers, MSM were more likely than other consumer to report T-cell counts under 200 (33% versus 25%) and viral loads over 10,000 (22% versus 12%).

A potential explanation for the difference in health status may be the disparity between MSM PLWH and others in terms of medication status. MSM consumers were significantly more likely than other survey respondents to be currently taking antiviral medications (83% versus 61%), protease inhibitors (57% versus 39%) and drugs to treat or prevent opportunistic infections (45% versus 35%). This difference applies to both white MSM and MSM of color, both of which are more likely than non-MSM to be taking HIV-related medications.

Providers of services to MSM noted that access to needed HIV medications was rarely an issue for their clients. Medical providers noted that compliance with complex dosaging regimens continues to be a problem for significant numbers of their patients. Several providers reported that their patients are taking “drug holidays.” In many cases, providers noted that non-compliance on the part of their clients has led them to suspend or end treatment regimens. Providers also stated that a growing percent of their MSM patients are experiencing debilitating side effects from HAART therapy, also leading physicians and clients to alter or terminate these regimens.

*“I am afraid that if anything changes, my health will go downhill like the Titanic. I have struggled with the beast, and can only be grateful I am doing this well. Sometimes I wish I would die because I have depression and episodes.” (White MSM PLWH)*

Providers noted that they are seeing increased morbidity among their long-term clients. The types of illness with which clients are presenting include heart disease, STD’s, liver disease, bacterial pneumonia and an increase in lymphomas. Clients also appear to be experiencing more dental problems related to long-term survival with HIV. In 1999, very few providers reported deaths among their clients during the year. In recent months, however, providers have noticed a steady increase in client deaths, particularly among long-term clients and among those who have failed repeatedly on HAART therapies.

The percent of MSM who are not in care appears to be very small, and has continued to decline in recent years. MSM of color were equally likely as white MSM to be using primary medical care (96% and 95%, respectively). Only 4% of MSM survey respondents reported not currently using outpatient medical care, with less than 1% stating that they could not access the service. The others stated either that they felt they did not need medical care, or preferred to receive primary care from a non-Western practitioner.

White MSM survey respondents reported high utilization of other clinical and support services as well. However, unlike in previous survey years, white MSM exhibited service utilization rates that were lower than MSM of color in most service categories. Of particular note is that white

MSM were less likely than MSM of color to report utilization of the Washington State ADAP program (50% versus 64%), food and meal programs (43% versus 57%), housing services (41% versus 51%) and transportation programs (27% versus 35%).

White MSM were also less likely than MSM of color to use HIV-related case management (79% versus 89%). White MSM in focus groups noted frustration with recent high turnover rates in local case management programs, but noted that they felt this had required them to become better self-advocates for services. Eighty-two percent of white MSM reported using one or more of the component services of client advocacy, with greatest utilization being medical information about HIV/AIDS.

MSM of color: As in previous years, the majority of MSM of color live in Central and South Central Seattle and in South King County. Homelessness has also increased in this population. Providers report that their MSM of color clients are generally of lower income levels than white MSM and are less likely to have private insurance coverage.

Providers also noted that their clients who are MSM of color were generally less likely than white MSM to openly identify as gay/bisexual in their communities, and were less likely to be involved in the gay community at-large. This is particularly true of Latino MSM (especially those who are non-English speaking) and American Indian/Alaska Native MSM (especially those who were raised in non-urban and/or reservation settings). This dual isolation decreases the chances that information about HIV/AIDS services is reaching MSM of color. Providers reported seeing increasing numbers of MSM without legal standing, including MSM immigrants and refugees from African and Latin American countries.

Survey results suggest that MSM of color are significantly more likely than white MSM to report themselves as being HIV+ and asymptomatic (40% versus 27%). Consistent with 1999 needs assessment results, MSM of color were significantly more likely than white MSM to be unaware of their T-cell counts (15% versus 5%) and viral load levels (19% versus 7%). Similar to white MSM, lack of access to outpatient medical care was not reported by MSM of color, either in surveys or in focus groups. However, providers of services to persons of color stated that education and information gaps about HIV issues may exist for their clients of color. In addition, immigrant MSM of color may also exhibit gaps in their understanding of the medical system in general. For some members of these populations, there may be a lack of trust in Western medical care or a cultural norm against seeking medical care unless debilitating clinical illness exists.

As with white MSM, access to prescription drugs did not emerge as a significant problem, but providers noted that medication compliance can be complicated by language barriers, cultural norms about taking medications and lack of trust in Western medicine. Even more so than with white MSM, providers of services to MSM of color report that many of the clients are unwilling to continue their medication regimens until adverse side effects can be negated. Nevertheless, 77% of MSM of color reported taking antiviral medications and 54% reported taking protease inhibitors. Thirty-four percent of MSM of color report having problems adhering to their medical regimens. These figures are lower than those reported by white MSM, but not statistically significant.

MSM of color were somewhat less likely than white MSM to report being diagnosed with mental illness (26% versus 33%). However, providers reported that they are seeing increases in the percent of their MSM of color clients who are presenting with depression and dementia. MSM of color were slightly more likely than white MSM to report having injected drugs in the past year (10% versus 8%). Homelessness appears to be a significantly greater problem among MSM of color than white MSM, with 20% of MSM of color survey respondents stating that they had been homeless in the past year versus 6% of white MSM.

MSM of color survey respondents reported somewhat higher utilization rates than white MSM of most other clinical and support services. Fifty-seven percent of MSM of color reported using peer support counseling, and 57% reported using food and meal programs. Utilization of client advocacy services was particularly high, with 88% of MSM of color reporting using one or more of the component services in this category, with greatest utilization being medical information about HIV/AIDS (for African American MSM) and legal assistance, such as help with immigration issues (for Latinos). Unlike previous years, the percent of MSM of color using dental care is now equal to the percent of white MSM using the service (both at 73%).

MSM/IDU: Providers of services to MSM drug injectors reported similar client demographics as non-injecting MSM, with the majority of clients being in their 30's. Almost all of the MSM/IDU clients currently being seen have incomes below poverty level. Providers described several of their clients as being "precariously employed."

Providers noted that about half of their MSM/IDU clients have had histories of incarceration, with many still actively involved with the court system. Consumer survey data supports this observation, with MSM/IDU survey respondents significantly more likely than non-IDU MSM to report having been in jail or prison in the past year (22% versus 4%). MSM/IDU respondents were also significantly more likely than other MSM to have been homeless in the past year (24% versus 7%).

MSM/IDU were also significantly more likely than other MSM to report having been diagnosed with a mental illness (57% versus 27%). Providers noted that they are seeing very high rates of depression among their MSM/IDU clients. This is particularly true for crystal meth users, who frequently present with attention deficit disorder, impacting their ability to maintain healthy lifestyles and adhere to treatment regimens.

*"Sometimes I want to go and loudly tell everyone what I have, but I really can't. There's too much stigma and fear out there. So I just told my family members, miles away from where I live. My children give me strength, along with the enigmatic future that sits in front of them and me." (White MSM/IDU PLWH)*

As first reported in 1997, providers noted that MSM/IDU clients who are responding well to protease inhibitors are healthier, while those who have not responded to the new medications are becoming sicker more rapidly. Providers noted that clients who are experiencing declines in their general health are less likely to be engaged in substance use treatment. Although providers noted a slight increase in HIV-related morbidity and mortality in this population, they noted that it was unclear if this trend was related to HIV or substance use. Providers also stated that their

clients are more knowledgeable about their own health status than in past years, and that they are more engaged in health care. MSM/IDU consumer survey respondents reported health status indicators which were statistically similar to the population of non-IDU MSM, with no major differences reported in level of HIV disease, T-cell count or viral load.

As with other populations, providers reported that their MSM/IDU clients had not experienced difficulty in accessing HIV medications, although adherence to medication regimens was problematic. Providers stated that adherence is generally reflective of the client's substance use pattern. Those who are having problems managing their substance use are most likely to have problems managing their HIV medication regimens. However, substance use counselors noted that they are seeing some improvement in the ways in which medical providers are working with their substance-using clients. In many cases, they noted, this means that doctors have begun to incorporate "harm reduction" modalities into their treatment styles. As a result, MSM/IDU survey respondents reported medication usage rates that were almost identical to other MSM.

### 3. Service Priorities

MSM survey respondents ranked primary medical care as their highest service priority, followed by dental care, case management, housing assistance and insurance programs (Table 23).

Unlike in 1999, significant differences emerged in several categories between the ways in which MSM and non-MSM prioritized services. MSM were significantly more likely than non-MSM to prioritize clinical services, such as primary medical care (67% of MSM versus 49% of non-MSM), dental care (59% versus 45%), and mental health therapy and counseling (31% versus 18%). Conversely, MSM were less likely to prioritize support services such as emergency financial assistance (28% versus 39%), food and meal programs (25% versus 36%), housing assistance (44% versus 60%) and client advocacy (33% versus 43%).

**Table 23. Service Priorities : MSM (n=410; 21 missing responses)**

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Ambulatory/outpatient medical care	274	67%
2	Dental care	241	59%
3	Case management	208	51%
4	Housing assistance/related services	181	44%
5	Insurance programs	172	42%
6	Drug prescription program (ADAP)	168	41%
7	Client advocacy	137	33%
8	Mental health therapy/counseling	126	31%
9	Alternative, non-Western therapies	124	30%
10	Direct emergency financial assistance	115	28%

Participants in the MSM focus group exhibited a high level of knowledge about the medical care system and HIV-related medical issues. They demonstrated strong self-advocacy skills in

general and expressed more confidence in their abilities to navigate the Continuum of Care than did other populations.

MSM of color: MSM of color ranked services in a fairly similar manner to white MSM, although the percentage of consumers in each population showed some differences. The top five service priorities for MSM of color were case management, dental care, housing assistance, primary medical care and insurance programs. Services prioritized by significantly higher percentages of MSM of color versus white MSM included housing assistance (57% versus 40%), client advocacy (46% versus 30%) and treatment adherence support (11% versus 4%). MSM of color were significantly less likely than white MSM to prioritize primary medical care (56% versus 70%).

MSM/IDU: Several significant differences emerged on the consumer survey in the ways in which MSM/IDU and non-IDU MSM prioritized services. Housing assistance and related services emerged as the top service priority for MSM/IDU, followed by case management, primary medical care, drug prescription programs, food/meal programs and dental care.

MSM/IDU were significantly more likely than other MSM to prioritize housing services (61% versus 41%). Based on input from focus group participants and providers, housing for persons with substance use histories presents major challenges. Although many of the MSM/IDU participants are now living in the Lyon Building (a 64-unit residence, primarily serving HIV+ client with substance use and/or mental health histories) many expressed concerns about their ability to remain clean and sober when living amid the persistent drug activity in the downtown environment.

Not surprisingly, MSM/IDU were significantly more likely than other MSM to prioritize substance use treatment (25% versus 7%). They were also more likely to prioritize adult day health programs (23% versus 9%), which may be as much a function of survey sampling as of actual priorities. MSM/IDU were significantly less likely than other MSM to prioritize dental care (36% versus 60%) and insurance programs (16% versus 44%).

#### **4. Service Gaps**

MSM PLWH identified gaps in alternative/non-Western therapies more than in other categories. Other highly ranked service gaps for this population include emergency financial assistance, counseling (peer support), client advocacy and housing assistance. (Table 24) Within the counseling (peer support) category, the highest gaps emerged in one-one peer support (14%) and support groups (11%); in client advocacy, the highest gaps emerged in peer advocacy (10%) and benefits counseling (10%); and in housing, the highest gaps were in help paying rent (14%) and help in finding low income housing (12%).

MSM were no more or less likely than other PLWH to identify gaps for almost all service categories. In only two categories did significant differences appear: MSM were less likely than other PLWH to identify gaps in emergency financial assistance (22% versus 34%) and food and meal programs (8% versus 18%).



**Table 24. Service Gaps: MSM (n=431)**

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Alternative/non-Western therapies	99	23%
2	Direct emergency financial assistance	93	22%
3	Counseling (emotional support)	85	20%
4	Client advocacy	81	19%
5	Housing assistance/related services	76	18%
6	Dental care	63	15%
7	Legal assistance	46	11%
8	Mental health therapy/counseling	43	10%
9	Referral	39	9%
10	Food meals	33	8%

Although alternative therapies were identified as the top service gap, the large majority of MSM survey respondents who use alternative therapies are also currently using Western medical care. Complimentary therapies, such as acupuncture and naturopathy, are most commonly employed to lessen the pain of opportunistic infections and/or the side effects of HIV medications. The greatest gap exists for those consumers who cannot afford to pay for these treatments themselves, whose insurance does not cover alternative care, and/or who do not qualify for Ryan White-funded services.

*“Working full time to make ends meet is very hard for those of us living with HIV. It is very hard to get assistance when one makes too much money. Too many agencies make you feel unwelcome and make you jump through too many hoops. You have to give up your quality of life to get any assistance.” (White MSM PLWH)*

Providers noted that they are seeing MSM clients in general who are seeking more help with financial assistance and insurance income benefits. Growing numbers of MSM clients are entering the system with no income and/or no insurance. Many clients are interested in re-training problems to assist them in getting back to work, but concerns exist about their ability to maintain ongoing employment and the potentially adverse effects employment may have on their benefits.

Providers reported service gaps for their MSM clients (and clients in general) in accessing Medicaid dental care due to a severe shortage of providers who are willing to accept this form of payment. Additionally, providers noted that coverage for complex procedures such as bridges, crowns and dentures is relatively impossible to secure for their clients. Consumers expressed frustration in navigating the dental care system, reporting extensive delays in accessing even basic dental care. Based on reports from providers, emergency dental appointments are also hard to secure.

MSM of color: MSM of color identified the same services as their five greatest service gaps as white MSM, although the rank order was different. The top five service gaps for MSM of color

were housing assistance, counseling (peer support), emergency financial assistance, alternative therapies and client advocacy.

In general, MSM of color were more likely than white MSM to report gaps in the provision of services. In several cases, these differences reached statistical significance. MSM of color were almost twice as likely as white MSM to identify gaps in housing services (29% versus 15%), particularly in help finding low income housing. Other key differences emerged in the areas of peer counseling (27% versus 17%), legal assistance (18% versus 8%), and adult day health (15% versus 2%). Within the category of peer counseling, the largest gap emerged in one-on-one peer support (24% versus 11%), with particularly large gaps noted by Latino MSM.

*“My wish is for some type of activity or work for Latinos living with HIV/AIDS, even if the pay was low. At least we could keep ourselves occupied. For example, even manual labor where we could establish our citizenship or something that could serve as a distraction.”*  
(Latino MSM PLWH)

Providers of services to MSM of color concurred with their clients’ assessment, noting greater service gaps than did providers of services to predominantly white MSM clientele. In addition to the services mentioned above, providers identified gaps in low income housing (particularly for undocumented PLWH) and transportation services (particularly for persons living in East and South King County).

MSM/IDU: Drug injecting MSM identified several different service gaps than non-injecting MSM. The three largest gaps reported by MSM/IDU were in the areas of mental health therapy, counseling (peer emotional support) and housing assistance, none of which ranked among the top three gaps for non-IDU MSM. MSM/IDU were more than three times as likely as non-injectors to identify gaps in substance use treatment and counseling (25% versus 7%) and over twice as likely to identify gaps in adult day health programs (23% versus 9%). MSM/IDU PLWH were also significantly more likely to identify gaps in housing assistance (61% versus 41%).

Providers of services to MSM/IDU PLWH echoed these sentiments. They noted that abstinence-based housing criteria are often impossible for their clients to adhere to. As a result, clients who are in gradual recovery (particularly those who have entered harm reduction programs) may lose what few housing options are available to them. Providers also noted that their clients may have problems accessing adult day health programs if they are not medically sick enough to meet eligibility criteria or if their substance use keeps them from participating on a regular basis.

## **5. Access Barriers**

Prior to 1999, MSM survey respondents were less likely than other populations (such as women and injection drug users) to identify barriers to accessing care services. In recent years this trend seems to have ended. Similar percentages of MSM PLWH identified access barriers as other populations, with no statistically significant differences emerging.

Consistent with other populations, MSM consumers identified a lack of information about available services as their main access barrier (Table 25). This is especially true for MSM who

are geographically and socially isolated from the gay/bisexual male community in central Seattle. In particular, lack of information about where and how to obtain services was identified as the major barrier that prevented MSM PLWH from accessing alternative therapies and emergency financial assistance.

**Table 25. Access Barriers: MSM (n=431)**

<b>BARRIER</b>	<b># OF VOTES</b>	<b>% OF RESP.</b>
Lack of information	111	26%
Financial (can't afford it)	82	19%
Eligibility (based on disability status)	34	8%
Eligibility (general)	33	8%
Quality of services is unsatisfactory	26	6%

Approximately one-fifth of MSM respondents identified access barriers related to financial constraints. For MSM whose income falls above 200% of FPL (the cutoff point for eligibility for Ryan White-funded services in the EMA), accessing services for which insurance coverage is less than optimal may be difficult. This includes mental health therapy, dental care and alternative/non-Western therapies.

As in 1999, MSM focus group participants expressed concern about staff turnover among case managers. The majority of participants had had more than one case manager during their illness, with several reporting having had three or four in a two-year period. They found this lack of continuity to be emotionally draining, particularly as they had to re-establish trust and build rapport with each new case manager. Several MSM in their 40's noted that succeeding generations of case managers appeared to be younger and younger, and that it was hard for them to feel confident in the abilities of staff whom they felt lacked experience in the HIV field.

Most providers felt that services were generally available to those clients who sought them or who followed through on referrals made by their medical providers or case managers. As in previous years, providers of services to MSM reported that access barriers for their clients were less dependent on sexual orientation than on issues of class, geography, race, and socioeconomic status. However, for MSM who are not "out" about their sexual orientation, accessing services may be limited by fear of disclosure and/or discomfort in perceived gay-identified environments.

As more clients are living longer with HIV, several of the most well-known HIV specialists in King County have closed their practices to new clients. Other providers are curtailing the number of new Medicaid patients they accept, due to low reimbursement rates. While access to primary care is not a widespread problem for PLWH in King County, new clients are finding that their preferred provider may be no longer available and that they may have to receive care from a provider who is potentially less established in the HIV field.

Mental illness is often another factor that limits access for clients. Providers noted that anger management issues are becoming increasingly common in their clients. This may serve as a

barrier to effective self-advocacy and lead to inappropriate interactions with providers and possible dismissal from services.

MSM of color: Two significant differences emerged in access barriers identified by MSM of color and white MSM. MSM of color were significantly more likely than white MSM to report being unable to access services due to lack of information (33% versus 23%), but less than half as likely to be unable to access services due to financial reasons (8% versus 23%).

*“Due to the side effects of the medications, I am waiting as long as I can before I start taking them. I am trying to find as much information as I can, to be prepared. I feel my friends are my support group, but I learn most of my information from my friends on medications and from treatment presentations.” (African-American MSM PLWH)*

As in previous years, focus group participants who were MSM of color stated that they often found themselves at a disadvantage in regards to knowledge of medical treatments and available services. This issue has lessened somewhat due to the emergence of new peer support and outreach programs for MSM of color, but an informational gap still exists for clients who are not yet familiar with the system. Financial barriers seem to be less of an issue for MSM of color than for white MSM due to the fact that a higher percentage of MSM of color seem to be eligible for Ryan White-funded services (77% of MSM of color report personal incomes under 200% of FPL versus 64% of white MSM).

Providers of services to MSM of color suggested that language barriers can serve as an obstacle for non-English speaking PLWH, such as immigrant Latinos and Asian/Pacific Islanders. Providers noted that their clients may feel culturally disenfranchised by both the mainstream gay white community and their communities of origin, which might disapprove of their sexuality. Finding peer social support can be extremely difficult under these circumstances.

MSM/IDU: No significant differences emerged in access barriers identified by MSM/IDU and non-injecting MSM. MSM/IDU were somewhat less likely than non-IDU MSM to identify barriers based on lack of information, perhaps because the MSM/IDU may have access to service information from both their HIV and substance use case managers.

Providers of services to MSM/IDU reported that substance use itself serves as the biggest barrier to accessing services for their clients. This also extends to clients' perceptions that they are being treated unfairly by providers in general. Clients who are active substance users may feel like they are being judged negatively by medical, mental health and social service providers and are denied access to medications and support services. If drug injecting clients perceive that they are stigmatized in this manner, they often will not access services or will not be honest about their substance use to providers.

Providers suggested the following recommendations about how to improve service delivery and client access for MSM living with HIV/AIDS:

- Advocate for more funding and identify alternative or previously-untapped funding streams. Providers felt that, as funding becomes tighter, a higher percent of funds is reserved for non-

MSM clients. As a result, their clients may feel that fewer services are available to them and that waiting lists for the services they desire are becoming more common.

- Improve access to dental care. Identify dental providers who are willing to accept Medicaid as well as those who can perform reduced-fee specialty care.
- Continue to educate all HIV providers about harm reduction strategies. Incorporate harm reduction into other program models, so that persons who are actively using and managing their use are not denied services.
- Increase adult day health slots for MSM/IDU, either within the existing program or at another agency.
- Develop more programs for MSM/IDU who are not primarily crystal meth users, including expanding programs for persons who are alcohol addicted.
- Expand housing options for non-AIDS disabled individuals. This includes developing more linkages between the AIDS housing field and housing opportunities in the mental health and substance use arenas.

## B. Injection Drug Users

*“I don’t do drugs any more, but when I did all the places required me to quit first and then they would help me. Come on! What’s up with that? My opinion is that if a person is on drugs, help them. If you treat the mental problem, the person would stop drugs on their own. I did.” (Homeless IDU PLWH, formerly incarcerated)*

### 1. Epidemiologic Profile

As in other parts of the Western United States, the number of cases of HIV and AIDS among drug injectors in King County is far less than those among gay and bisexual men. However, the percent of cases attributable to injection drug use (IDU) in King County is on the rise. While the proportion of cumulative AIDS cases that were acquired via drug injection is 6%, in recent years nearly 10% of case have been attributed to IDU risk.

Status and trends in AIDS cases: There are an estimated 150,000 people in King County at increased risk of HIV infection because of illicit drug use or alcohol abuse. About 15,000 of these are at increased risk due to drug injection. The estimated number of HIV+ heterosexual IDU in King County is 400 to 650 (midpoint=525). The estimated number of men who have sex with men and also inject drugs is 600 to 900 (midpoint=750).

AIDS in female and heterosexual male IDU was first reported in King County in 1986. By the end of 2000, 346 cases had been diagnosed and reported in this group, representing about 6% of all King County AIDS cases. An additional 100 IDU had been reported with HIV infection, but had not developed AIDS.

The proportion of cases attributed to drug injection among heterosexuals has increased from about 3% of cases in 1983-1988 to 6% in 1992-1994, and 10% in 1998-2000. While the number of male IDU in King County reported with AIDS is higher than the number of female IDU, the proportion of male AIDS cases whose infection was attributed to IDU is 4% compared to 31% among females.

Injection drug use is a relatively more important route of HIV transmission for King County African Americans with AIDS (14% of cases), and Native American/Alaska Natives (21%) and Latinos/Latinas (10%) compared to whites (4%) or Asian/Pacific Islanders (3%).

HIV seroprevalence: In unlinked surveys conducted by Public Health – Seattle & King County of more than 7,000 drug users entering King County drug treatment programs between 1988-1999, 1.5% tested HIV positive. HIV prevalence among clients entering drug treatment in King County has hovered around 2% and has not changed significantly over the 12 years that these unlinked HIV surveys have been conducted.

### 2. Service Trends

According to information from providers of services to injection drug using PLWH, the overall demographics of the population have changed relatively little in the past two years. The population of IDU PLWH is still primarily male (approximately 60% of clients served), with

continuing increases in the number of HIV+ female IDU being seen. Approximately half of the male clients are white, with the rest almost equally divided between African-Americans and Latinos. Providers noted that their female IDU PLWH caseloads tend to be fairly diverse, including quite a few Native Americans and African Americans. Providers noted that most of their clients are in the 35-45 age range, with increasing numbers of younger clients (under the age of 25) using services in the past two years. IDU respondents to the consumer survey demonstrated almost equal sex and race demographics as non-IDU's, with 82% of IDU being male (versus 85% of non-IDU) and 72% identifying as white (versus 71% of non-IDU).

As in previous years, providers reported that almost all of their clients are living at or below the poverty level. Very few have legitimate jobs, although some sell drugs to support their addiction. IDU PLWH were significantly more likely than non-IDU survey respondents to report incomes below 100% of Federal Poverty Guidelines (49% versus 38%). Homelessness is also a major, and growing, problem in this population. Survey respondents with substance use histories were almost four times as likely as non-IDU PLWH to have been homeless in the past year (31% versus 8%).

Providers noted that well over half of their IDU clients have been in jail or prison, mostly for drug-related offenses. In many cases, incarceration is chronic, with clients returning to jail for repeat offenses. Providers also noted that the increased presence of law enforcement in downtown Seattle has increased the likelihood that their clients will become involved in the criminal justice system. Consumer survey data support this statement, as IDU PLWH were significantly more likely than other consumers to have been incarcerated in the past year (26% versus 4%).

As noted in previous years, providers are seeing increasing multi-drug use among their IDU clients, including rising rates of alcohol abuse. Methamphetamine use continues to increase, particularly among male IDU. Use of crack cocaine is more prevalent among female IDU. Heroin injection is frequently reported for both male and female IDU. Providers also noted that male IDU who have been in methadone treatment for heroin use may relapse into crack use.

Harm reduction programs continue to work well for many of the IDU PLWH who have accepted this approach, with providers reporting that these clients are using more safely, participating in needle exchange programs and entering and remaining in treatment in greater numbers and for longer periods of time than in past years. Conversely, providers also noted that they are seeing an increase in the number of clients who are sharing needles and engaging in unprotected sex.

*“Drug users aren’t getting care because they’re still using. They’re not responsible. I probably know fifteen people that are HIV+ who are not getting care. You need to develop a clinic, give them their hit of heroin and then provide medical care, like that experimental clinic in London. “ (Female IDU PLWH)*

Providers continue to report seeing increasing percentages of their IDU PLWH clients who are both chemically dependent and mentally ill. IDU survey respondents were significantly more likely than other PLWH to report having been diagnosed with a mental illness (52% versus 27%). The percent of IDU survey respondents who reported mental illness increased by 11% in

the past two years. Many of these clients are chronically mentally ill, with high levels of depression, bipolar disorder and cocaine-related psychosis.

Data from the 2001 consumer survey reveal several differences between HIV-related health care status between IDU PLWH and non-IDU PLWH. Although IDU were equally as likely as other consumers to be diagnosed with AIDS (as opposed to being HIV+, non-AIDS), IDU consumers were significantly more likely to have had their AIDS diagnosis based on low T-cell counts, rather than opportunistic infections. No significant differences emerged between IDU and non-IDU PLWH regarding the types of HIV-related medications they were taking, but IDU were significantly more likely to report having problems with HAART adherence (38% versus 29%). Although providers reported no actual difficulties for their IDU clients in accessing prescription medications, they did note that clients might perceive that medical providers will not put them on HAART therapy because of their substance use. Some clients may feel compelled to hide their substance use histories from their medical providers for this reason.

Providers reported increasing HIV-related morbidity among their IDU clients. In particular, female IDU are experiencing more hospitalizations and opportunistic infections, especially if they are homeless. Cervical and gynecological problems are also increasing in this population. In many cases, IDU PLWH discover their HIV status after being admitted to the hospital with life-threatening illnesses. Several participants in the IDU focus group reported learning about their HIV status in detoxification facilities, in prison or upon being hospitalized.

Based on responses to the 2001 consumer survey, service utilization by drug injecting PLWH was similar in most categories to that exhibited by other populations. Ninety-seven percent of IDU PLWH reported current utilization of primary care, and 50% reported using the State's AIDS Drug Assistance Program.

Both providers of services to IDU and IDU consumers themselves acknowledged the importance of case management in helping drug-injecting PLWH negotiate the care service system. IDU PLWH were more likely than other populations to use case management services (87% versus 77%). Drug injecting PLWH are also more likely than other consumers to be using food and meal services (60% versus 46%), and housing assistance (62% versus 42%). In both cases, these figures represent significant increases in utilization from the 1999 consumer survey. IDU survey respondents were less likely, however, to use client advocacy (71% versus 85%) and insurance continuation programs (39% versus 60%).

The number and percent of IDU PLWH who are utilizing substance use treatment services has also risen during the past two years. In 1999, 32% of IDU survey respondents reported using substance use counseling services. In 2001, this figure rose to 42%. This is consistent with utilization reports from service providers, who report increases in the number of clients being assessed for treatment, entering one-on-one or group counseling, and entering in-patient residential treatment.



### 3. Service Priorities

Injection drug using PLWH identified housing assistance and related services as their highest service priority in 2001. Housing services were followed by case management, primary medical care, prescription drug programs and food/meal programs (Table 26).

IDU PLWH were significantly more likely than other consumers to identify housing services as a priority (64% versus 45%). As previously noted, the rate of homelessness in this population is far greater than in non-IDU PLWH. Lack of access to permanent housing can increase the likelihood of relapse, particularly for IDU who are recently discharged from treatment facilities.

**Table 26. Service Priorities: Injection Drug Users  
(n=58; 7 missing responses)**

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Housing assistance/related services	37	64%
2	Case management	32	55%
3	Ambulatory/outpatient medical care	31	53%
4 (tie)	Drug prescription program (ADAP)	22	38%
4 (tie)	Dental care	22	38%
6	Food/meals	20	34%
7	Alternative/non-Western therapies	19	33%
8	Client advocacy	18	31%
9	Mental health therapy/counseling	17	29%
10	Counseling (emotional support)	16	28%

As in past years, providers of services to injection drug using PLWH were much more likely than consumers themselves to rate substance use treatment and counseling as a priority service for this population. This may be due to consumers' beliefs that substance use treatment is not an HIV/AIDS-related service or consumer denial about the need for this service. However, focus group participants (each of whom was currently either in recovery or a harm reduction program) stressed the importance of substance use counseling in improving their overall health and emotional well-being.

### 5. Service Gaps

Injection drug using PLWH identified service gaps that were relatively similar to those reported by other populations. The number one service gap identified by injection drug using consumers was alternative therapies, followed by counseling (peer support), emergency financial assistance, dental care and housing assistance (Table 27).

Unlike previous years, IDU survey respondents were less likely than other consumers to report unmet service needs. The only two services that were more likely to be seen as gaps by IDU were alternative therapies (28% versus 22%, which is not statistically significant) and substance

use treatment (12% versus 3%). Focus group participants noted that they had little trouble accessing substance use treatment once they determined they were ready for it. Each participant noted that they knew several current IDU who were either HIV infected or at high risk of infection who were not yet ready to seek substance use treatment, some of whom were also not accessing primary care for treatment of their HIV.

**Table 27. Service Gaps: Injection Drug Users (n=65)**

<b>RANK</b>	<b>SERVICE</b>	<b># OF VOTES</b>	<b>% OF RESP.</b>
1	Alternative/non-Western therapies	18	28%
2	Counseling (emotional support)	11	17%
3	Direct emergency financial assistance	10	15%
4 (tie)	Dental care	9	14%
4 (tie)	Housing assistance/related services	9	14%
6 (tie)	Substance use treatment/counseling	8	12%
6 (tie)	Mental health therapy/counseling	8	12%
8 (tie)	Client advocacy	7	11%
8 (tie)	Legal assistance	7	11%
10 (tie)	Insurance programs	6	9%
10 (tie)	Food meals	6	9%

Providers were in agreement with this sentiment. They noted that increasing numbers of their clients are now using substance use treatment and trying to get addiction under control. However, they reiterated that it may take a very long time for the provider to persuade clients to access treatment, requiring that providers build trust between themselves and the client before this engagement can occur. They also stressed the importance of having chemical dependency services immediately accessible when the client is prepared to receive them. They noted that Ryan White vouchers have been very helpful in avoiding long waiting lists for ADATSA services.

Providers of service to injection drug using PLWH frequently mentioned housing as the main service that their clients were unable to access. Providers noted a lack of affordable housing in general for low income persons in King County, particularly for their clients who are living at or below 100% of poverty level. They also noted a shortage of emergency and transitional programs for clients who are discharged from in-patient facilities. They noted that these clients are at high risk of failing in their attempts to maintain housing because they are likely to relapse into substance abuse.

Although neither consumers nor providers identified a barrier in accessing medical care, providers did note that many of their clients are uncomfortable with the kind of care they receive. Some of this relates to client perceptions that providers will treat them with less respect because of their substance use histories. Providers stated that this used to be much more of an historical

reality, but that in recent years they have seen far fewer cases of ill-treatment of their clients. Nevertheless, the perception lingers and may serve as a barrier to clients receiving care.

## 5. Access Barriers

IDU respondents to the consumer survey identified similar access barriers as other populations, with lack of information and financial barriers being the two most frequently noted (Table 28).

**Table 28. Access Barriers: Injection Drug Users (n=49)**

BARRIER	# OF VOTES	% OF RESP.
Lack of information	15	23%
Financial (can't afford it)	10	15%
Eligibility (based on disability status)	5	8%
Haven't asked	4	6%
Eligibility (non-specific)	4	6%

Consumers in focus groups and providers acknowledged that chemical dependency and general life chaos often take priority over health care and social service needs. Thus, services may not be accessed until the client is in severe crisis. Drug injecting clients usually enter into the HIV care system with little awareness of available services and may become over-reliant on the services of case managers or outreach workers to help them access services. Providers also noted that low self-esteem among IDU PLWH can complicate access to care.

*“Nobody knows about the virus on the streets, especially the people that are prone to getting it. The addict lifestyle here is totally different then where I came from. Here I say “I have the virus” and other addicts say, “What virus?” People don’t have a clue. (Female IDU PLWH)*

Misinformation about services that is circulated among IDU on the street can also be problematic, such as the previously-mentioned belief that medical providers will not give IDU clients appropriate care. Several focus group participants expressed frustration that they were unable to access pain medications, often because the provider felt that these medications would be dangerous when combined with the street drugs that the client was taking. Some participants also felt that providers were less likely to recommend HAART therapy to their IDU clients, although others acknowledged that active substance use made adherence with medication regimens much harder.

Unlike previous years, IDU were no more likely than non-IDU PLWH to identify financial barriers in accessing HIV services. However, because most IDU PLWH are living at or below poverty level, financial concerns in general weigh heavily in their ability buy groceries and clothing and afford transportation. Providers noted that clients who are still actively using substances may opt to use what little funds they have to purchase drugs, alcohol or cigarettes rather than paying for rent, utilities and other necessities. As one provider noted, “For clients who earn their money through drug sales or sex work, time spent waiting for appointments and

seeing social workers and doctors is money lost. Perhaps if they were getting [more financial assistance], they would be able to break the cycle of the daily hustle.”

*“My biggest obstacle in looking for housing is my background in the penitentiary. Places like HUD, then tend to want to keep that in front of your face even though you’ve finished the time. Housing has been available to me, but it’s in the danger zone area, it’s right where the drug market is. They’ll put you in one of those places where there is constant drug activity.” (African-American male IDU PLWH)*

As in previous years, providers and IDU consumers also noted that housing policies that demand absolute sobriety can pose obstacles. Although sobriety houses are safe and affordable for clients, many programs will not accept clients that are going through methadone treatment. This can be particularly problematic for clients whose chemical dependency counselors have helped them accept a harm-reduction modality, while other service programs promote abstinence.

Providers offered several suggestions about how to improve service delivery and client access for injection drug using PLWH:

- Develop more housing options for IDU similar to the Lyon Building, a 64-unit residential facility primarily for persons multiply diagnosed with HIV/AIDS, chemical dependency and/or mental illness. The harm reduction modality adopted by the Lyon Building allows persons in recovery to work towards sobriety without the danger of being evicted for relapse problems. In particular, one provider suggested a Lyon Building format specifically for female IDU PLWH.
- Identify more funding to increase the number of treatment slots. Trying to find treatment on demand is difficult and detox beds are limited. Creating mobile methadone treatment options would be particularly helpful.
- Offer on-site substance use and mental health counseling in a variety of venues. Develop drop-in sites where homeless IDU can come to “hang out” and receive food, meals and other services.
- Continue to train service providers across the Continuum of Care about harm reduction principles and processes. The more that service providers can accept the harm reduction model, the greater the chance of effective inter-system collaboration. Providers need to develop strong rapport-building skills to ensure that their IDU clients maintain involvement in services.
- Stress the importance of culturally-appropriate care. This includes not only understanding and working with racial and linguistic diversity, but acknowledging that there is a culture of substance-using individuals who may bring different values and health beliefs to the care system.

## C. People of Color

*“Services are getting harder to access. I think it’s getting worse, just with the challenges around funding. And it’s not about race, it’s about funding. What do I have to look forward to? I’m tired of getting \$10 in food stamps!” (African-American male PLWH)*

(NOTE: Information is reported by specific sub-populations of communities of color, based on data from service providers, consumer survey respondents and consumer focus group participants. Data tables include aggregate statistics from consumer survey respondents who identified as African-American (n=62) or Latino/Latina (n=52). The number of American Indians/Alaska Natives (n=14) and Asians/Pacific Islanders (n=13) who responded to the survey is insufficient from which to develop useful data tables for these populations or on which to run tests for statistical significance. As a result, information presented regarding PLWH from these populations is based primarily on key informant provider interviews and focus group responses.)

### 1. Epidemiologic Profile

In Seattle-King County, as in the United States as a whole, epidemiologic data indicate that HIV and AIDS have disproportionately affected African-Americans, American Indians/Alaska Natives, and Latinos/as as compared to whites or Asian/Pacific Islanders. The racial disparity is even greater among women and children as compared to men.

Status and trends in AIDS cases: Through December 2000, 1,214 people of color residing in King County were reported with AIDS, representing 20% of the 6,096 total AIDS cases. AIDS rates in recent years (1997-1999) demonstrate the epidemic’s disproportionate impact, with rates in African-Americans, Latino/as and American Indian/Alaska Natives being over three times that of whites in King County. AIDS rates in Asian/Pacific Islanders, however, continue to be significantly lower than whites. A comparison of King County 1998 population estimates and reported AIDS cases in King County for the three-year period of 1997-1999 is reported below (Table 29).

**Table 29. Comparison of King County Racial Composition  
with Recent AIDS Case Statistics (1997-1999)**

	King County	(% of pop.)	AIDS Cases (1997-1999)	(% of cases)	AIDS case rate per 1000,000 population
White	1,332,575	(80%)	399	(67%)	10.0
African American	88,993	( 5%)	97	(16%)	36.0
Latino/Latina	57,716	( 4%)	64	(11%)	35.9
Asian/Pacific. Islander	168,188	(10%)	17	( 3%)	3.4
Am. Indian/AK Native	18,328	( 1%)	18	( 3%)	33.0
<b>TOTAL</b>	<b>1,665,800</b>	<b>(100%)</b>	<b>595</b>	<b>(100%)</b>	<b>11.9</b>

Racial disparities are greatest among women and children. In 1997-1999, the average annual rate of AIDS for African-American females (17.3 per 100,000) was 19 times greater than that of whites females (0.9 per 100,000). Also, eight (57%) of the 14 maternally-acquired acquired

pediatric AIDS cases reported in King County through December 2000 were born to women of color.

More African-American and American Indian/Alaska Native men and women acquire HIV from injection drug use as compared to other groups. The percent of AIDS cases by race for selected HIV exposure categories for males and females are given in Table 30.

**Table 30. AIDS Cases by Race and Selected HIV Exposure Categories (12/31/00)**

<b>MALES (N=5,803)</b>	<b>White</b>	<b>Afr-Am</b>	<b>Latino/a</b>	<b>A/PI</b>	<b>AI/AN</b>
MSM non-injectors	82%	58%	72%	83%	57%
MSM drug injectors	11%	11%	8%	5%	27%
Heterosexual drug injectors	3%	14%	10%	3%	9%
Heterosexual non-injectors	1%	4%	3%	1%	1%
<b>FEMALES (N=293)</b>	<b>White</b>	<b>Afr-Am</b>	<b>Latino/a</b>	<b>A/PI</b>	<b>AI/AN</b>
Drug injectors	27%	34%	6%	0%	71%
Heterosexual non-IDU	51%	37%	63%	38%	24%
Transfusion recipients	8%	4%	6%	13%	0%
Undetermined	12%	21%	13%	50%	6%

HIV seroprevalence: Between 1,600 and 2,340 (midpoint=2,000) people of color residing in King County are estimated to be HIV positive, compared to 4,440 to 6,660 whites. By race/ethnicity, this includes 840 to 1,260 African-Americans, 480 to 720 Latino/as, 120 to 180 American Indian/Alaska Natives, and 120-180 Asian/Pacific Islanders.

In surveys of King County women giving birth from 1989 to 1995 (when the survey ended), the percent of African-American women testing HIV positive (0.3%) was ten times the percent of white women (0.03%).

## **2. Service Trends**

African-Americans: Providers of services to African-American PLWH reported that their client caseloads are approximately two-thirds male, with no significant changes in the gender make-up in the past several years. Similar to epidemic figures, African-American survey respondents were significantly more likely than whites to be female (37% versus 8%) and identify as heterosexual (45% versus 12%). African-American survey respondents were also more likely than whites to report incomes under 100% of Federal Poverty Level (50% versus 32%) and Seattle, rather than East or South King County, residency (85% versus 76%).

*“Why do people have to be unbelievably poor to get assistance? I struggle check to check. I hardly ask for help and yet when I get up the nerve to do just that, I’m embarrassed with a “you don’t qualify” response. My biggest fear is what am I going to do when I can’t work and I don’t have any coverage and I can’t afford any.” (African-American female PLWH)*

Although providers note that increasing numbers of their African-American clients are currently taking HIV-related medications than in past years, adherence issues continue to be a growing

problem. Providers noted that access to HIV-related medications is not a problem, but that many of their clients do not want to start HAART regimens, either because they do not trust the medications or are wary of side effects. However, one provider noted that her African-American clients have become better at addressing adherence issues with their medical providers, and are less likely to discontinue their medications without first discussing this issue with their providers.

Despite these positive changes, African-American PLWH survey respondents continue to be significantly less likely than whites to be taking all forms of HIV-related medications. This includes lower rates of taking antivirals (63% versus 83%), protease inhibitors (35% versus 56%) and medications to treat or prevent opportunistic infections (31% versus 47%). Of PLWH who reported taking at least one form of HIV-related medications, African-Americans were significantly more likely than whites to report having adherence problems (42% of African-American PLWH versus 32% of whites).

Several other differences emerged regarding health status between African-American and white survey respondents. African-Americans were statistically more likely to report themselves as HIV+, without symptoms (42% versus 26%) and almost four times less likely to have been diagnosed with AIDS based on opportunistic infections (8% versus 31%). However, African-Americans were also significantly more likely than whites to report not knowing their current T-cell counts (24% versus 7%) nor their viral loads (26% versus 9%).

African-American survey respondents were four times more likely than whites to report having been homeless in the past year (24% versus 6%). Providers of outreach services to African-American PLWH noted seeing an increase in the number of homeless clients they are encountering and helping engage into services.

No significant differences emerged on the consumer survey regarding rates of mental illness and substance use reported among African-American versus white PLWH. However, providers reported that large and growing numbers of their clients suffer from depression. Many clients have long-term histories of mental health problems, although many are in denial about the need to seek professional help. Substance use issues continue to be widespread among African-American PLWH, although providers noted a slight decrease in the number of clients who are using and a slight increase in the number who are in (or seeking) treatment.

In general, African-American survey respondents reported higher utilization rates of most services than did white consumers. In previous years, African-American PLWH were significantly less likely than whites to use outpatient medical care. On the 2001 survey, this difference was no longer statistically significant (90% of African-Americans using primary medical care versus 94% of whites). However, African-American consumers were more likely to rely on the Washington State AIDS Drug Assistance Program for their HIV-related medications than whites (61% versus 51%).

African-Americans were significantly more likely than whites to use transportation services (50% versus 29%), peer counseling services (66% versus 55%), emergency financial assistance (48% versus 38%), health education/risk reduction programs (35% versus 15%), and housing assistance (61% versus 50%). The single service that was more likely to be used by whites than

African-Americans was alternative, non-Western therapies (41% of whites versus 31% of African-Americans).

Of special note is the increase in HIV+ African refugees who have re-settled in King County. The largest groups are from Ethiopia and Eritrea, but almost all West African countries are represented. Approximately one-third of these clients are women. Most of the African PLWH live in the Rainier Valley in Seattle, with the remainder located in South King County.

Providers of services to African refugee PLWH report that their clients are generally in good health. Once introduced to the HIV care system, the clients have had good access to medical care and prescription medications. Co-morbidities such as mental illness and substance use are rare in this population.

Latino/Latinas: Providers of services to Latino/a PLWH reported that their client caseloads are predominantly male, although a growing number of Latinas have begun to enter the HIV care service system in recent years. While the difference is not as marked as with African-American survey respondents, Latino/a survey respondents were significantly more likely than whites to be female (19% versus 8%) and identify as heterosexual (29% versus 12%).

Latino/a survey respondents were more likely than all other populations to report incomes under 100% of Federal Poverty Level (71% of Latino/as versus 32% of whites and 52% of African-Americans). Providers noted that a large percentage of their clients have no income at all and are entirely dependent on government assistance. Latino/as were also significantly more likely than other consumers to report living in South and East King County (35%, versus 24% of whites and 15% of African-Americans).

Providers reported that their clients' health has generally improved during the past two years, with most clients being HIV+ and asymptomatic. Although clients may report non-disabling HIV-related symptoms, morbidity and mortality seem to have decreased in this population since 1999. As with African-American clients, providers noted that increasing numbers of their Latino/a clients are currently taking HIV-related medications than in past years. The percent of Latino/a survey respondents who report taking HIV-related medications has remained fairly constant from 1999, with no significant differences emerging between whites and Latino/as regarding medication status.

Providers noted that adherence problems continue to be common among their Latino/a clients. Providers stressed the importance of providing ongoing support and motivation to their clients to assist them with medication adherence. Several noted that long-term adherence has now been achieved for many clients, crediting improved communication between medical and social providers and Latino/a clients. As a result, of all PLWH who reported taking at least one type of HIV-related medication, a smaller percentage of Latino/a survey respondents reported adherence problems (30%) than did whites (32%) or African-Americans (42%).

Similar differences emerged regarding health status between Latino/a and white survey respondents as were noted between African-American and white PLWH. Latino/as were statistically more likely to report themselves as HIV+ without symptoms (40% versus 26%) and



less likely to have been diagnosed with AIDS based on opportunistic infections (21% versus 31%). However, Latinos/as were also significantly more likely than whites to report not knowing their current T-cell counts (23% versus 7%) nor their viral loads (31% versus 9%).

Latino/a survey respondents were over three times more likely than whites to report having been homeless in the past year (21% versus 6%). Providers of outreach services to Latino/a PLWH noted that as many as one-third of the clients had been homeless at one time or other during the past year. However, case managers with large Latino/a caseloads noted that their clients were successfully maintaining housing stability after placement in HIV-related housing facilities.

Latino/a PLWH were significantly less likely than white survey respondents to report mental illness and substance use. Only 15% of Latino/as reported having been diagnosed with mental illness, versus 33% of whites. However, providers reported that depression is fairly common among their clients. They expressed a need to educate Latino/a PLWH about mental health issues and services, noting that cultural differences in the ways which one understands mental illness often keep their clients from seeking services.

Substance use seems to be increasing in the population of Latino/a PLWH, with providers noting that alcohol abuse is widespread. Many clients are in denial about their use, however. As one provider noted, “If it’s not a crime, it’s not a problem.” The percentage of Latino/a survey respondents who reported using injection drugs was significantly lower than for either whites or African-Americans (2%, versus 8% and 8%, respectively), as was the percentage of Latino/as who reported use of other street drugs (6% versus 15% and 21%, respectively).

In most service categories, Latino/a survey respondents reported similar utilization rates as white consumers. In previous years, Latino/a PLWH were significantly less likely than whites to use outpatient medical care. On the 2001 survey, this difference was no longer statistically significant (87% of Latino/as using primary medical care versus 94% of whites). However, Latino/a consumers were significantly more likely than whites to use treatment adherence support services to assist them in taking their medications as prescribed, particularly from case managers and client advocates (40% of Latino/as using this service versus 27% of whites).

Latino/as were significantly more likely than whites to use housing services (40% versus 27%) and health education/risk reduction programs (25% versus 15%). As previously noted by providers, their Latino/a clients did not tend to be connected to mental health services. This statement is supported by survey data, which reveal that Latino/as are significantly less likely than whites to use mental health therapy and counseling (29% versus 50%). The single other service that was more likely to be used by whites than Latino/as was dental care (73% of whites versus 62% of Latinos/as).

American Indian/Alaska Natives: Providers of service to American Indians and Alaska Natives report that their caseloads are predominantly comprised of males, although increasing numbers of women have entered the system in recent years. The majority of American Indian clients live below the poverty level, and have been living in poverty most of their lives. Transmission risk among men is predominantly through homosexual activity, although men may not self-identify as gay or bisexual. Among women, heterosexual transmission is most common. Demographic

indicators among the relatively small number of American Indian survey respondents are consistent with provider reports.

Providers report chronic alcohol and drug use among the majority of their American Indian PLWH population, with heroin and cocaine being the most commonly used drugs. Increasing numbers of clients have sought treatment in the past two years, including entering harm reduction programs and methadone treatment. Providers also report that the majority of their American Indian PLWH clients have mental health issues. More clients are accessing mental health services than in previous years. A higher percentage of American Indian consumer survey respondents report histories of mental illness, injection drug use and use of other street drugs and recent incarceration than other consumer sub-populations.

Providers reported that their clients' health has generally declined during the past two years, with more clients experiencing HIV-related health symptoms. This is particularly true of female American Indian PLWH. Providers report an increase in the number of clients who are progressing from HIV+ to AIDS diagnoses, including long-term survivors whose health is now failing.

Providers and focus group participants noted that access to primary care is good when the consumer is ready to accept it. Most of the American Indian focus group participants reported learning they were HIV+ in non-medical settings, such as in jail, at homeless shelters or through drug treatment facilities. In several cases, the knowledge of their HIV serostatus was accompanied with an AIDS diagnosis. Current access to HIV-related medications is reported as good, although adherence problems are common. Providers noted that cultural issues regarding taking Western medications complicate adherence with HAART therapy.

As noted in previous assessments, a distinction exists between American Indian/Alaska Natives who are reservation-identified (having been born, raised and/or currently living on tribal lands) versus those who are more acculturated into the mainstream. This distinction may influence clients' willingness to accept non-Indian provided services, trust in non-Indian providers and overall knowledge about HIV. For reservation-identified Indians, developing trust in an unfamiliar provider and/or service system may be a lengthy process. Nevertheless, providers reported that their American Indian clients are more willing to accept referrals to non-Indian service providers than in past years. American Indian/Alaska Native survey respondents reported similar rates of service utilization as other populations.

Asian/Pacific Islanders: Demographic indicators for A/PI PLWH remain relatively unchanged during the past two years. Providers report that their A/PI clients are almost exclusively MSM, with relatively few cases attributed to injection drug use. This is consistent with the limited response to the consumer survey, with almost all of the thirteen A/PI respondents being males who report MSM transmission risk. Clients represent a wide spectrum of Asian nationalities and languages, including Chinese, Vietnamese, Filipino, Korean, Laotian, Japanese, Samoan, Hmong and native Hawaiian. Although most clients speak at least limited English, language barriers are present for new arrivals to the United States. Most clients are low income or below the poverty level.

Providers reported that many of their clients have remained in stable health during the past two years, with very little severe HIV-related illness. Access to HIV medications is not a problem, although cultural distrust of HIV medications may exist for newly-arrived A/PI. Eleven of the thirteen A/PI survey respondents are currently taking some form of HIV medication, with approximately half reporting adherence problems.

Providers noted that co-morbidities among their A/PI PLWH clients are relatively low. Some clients suffer from depression, but other mental illness diagnoses are rare. As previously noted, substance use, including injection drug use, is also uncommon in this population. A/PI survey respondents were also less likely to be homeless than other PLWH of color.

As noted in previous needs assessments, service utilization patterns for A/PI PLWH seem to be dependent on the client's level of acculturation into the mainstream. Asian/Pacific Islanders who are more integrated into the larger community and who do not have language and cultural barriers are reported as seeking services from a wide variety of HIV/AIDS service providers. Those clients who are first generation A/PI are more likely to restrict their services to agencies targeting Asian communities.

The limited number of A/PI survey respondents reported higher utilization rates in most service categories than other populations. Utilization rates were particularly high for medical care, case management, client advocacy, Washington State's AIDS Drug Assistance Program and emergency financial assistance.

### **3. Service Priorities**

African-Americans: African-American survey respondents ranked housing assistance and housing related services as their number one service priority (Table 31). Case management tied with dental care as the second highest service priority, followed by primary medical care, client advocacy and insurance programs. Within the category of client advocacy, the highest prioritized service components were medical information about HIV/AIDS (23%) and benefits counseling, other than by a case manager (21%).

Continuing a trend observed in previous assessments, African-Americans were significantly more likely than whites to prioritize housing assistance (56% versus 42%). Providers noted that securing low income housing is an issue for many of their clients. Even if subsidies are increased, housing can still be difficult to access due to prior criminal records and current substance use. As previously noted, African-American consumers were also less likely than whites to be AIDS disabled and therefore may not qualify for housing based on disability status.

African-American PLWH were less likely than whites to prioritize outpatient medical care, with only 50% of respondents listing this service as a priority as opposed to 69% of white PLWH. This may be related to the fact that African-American respondents were more likely than whites to report that they were HIV+ and asymptomatic and significantly less likely to have been diagnosed with an opportunistic infection.

**Table 31. Service Priorities: African-Americans (n=54; 8 missing response)**

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Housing assistance/related services	30	56%
2 (tie)	Case management	29	54%
2 (tie)	Dental care	29	54%
4	Ambulatory/outpatient medical care	27	50%
5	Client advocacy	26	48%
6	Insurance programs	23	43%
7	Food/meals	20	37%
8	Direct emergency financial assistance	18	33%
9	Counseling (emotional support)	16	30%
10	Drug prescription programs (ADAP)	14	26%

Among African immigrant PLWH, providers noted that case management is extremely important. These clients enter the system with little or no knowledge of available services. In many cases, they are unfamiliar with HIV medical care in general. Legal assistance in coping with immigration issues is also of high importance to this population.

Latino/Latinas: Latino/a survey respondents ranked housing assistance and housing related services as their number one service priority (Table 32). This was followed by case management, dental care, primary medical care and client advocacy. Within the client advocacy category, the most highly prioritized services were medical information about HIV/AIDS (21%), interpreter services (17%) and benefits counseling (15%).

Latino/a consumers were significantly more likely than whites to prioritize housing assistance and related services (69% versus 42%). Providers noted that housing needs among their clients have increased in recent years, particularly due to the increasing number of non-resident clients who have arrived in King County. Seattle Housing Authority is now checking immigration status for all applicants, making it more difficult for persons without legal standing to qualify for housing assistance. Additionally, as noted previously, many Latino/a PLWH have low or no incomes, and cannot afford to cover security deposits for rental apartments.

**Table 32. Service Priorities: Latino/Latinas (n=48; 4 missing response)**

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Housing assistance/related services	33	69%
2	Case management	28	58%
3	Dental care	27	56%
4 (tie)	Ambulatory/outpatient medical care	26	54%
4 (tie)	Client advocacy	26	54%
6	Insurance programs	25	52%
7	Direct emergency financial assistance	23	48%

8	Drug prescription program (ADAP)	16	33%
9	Legal assistance	13	27%
10	Alternative, non-Western therapies	11	23%

Latino/a consumers were significantly more likely than whites to prioritize client advocacy services (54% versus 30%). Latino focus group participants noted that information about HIV disease and medications is difficult to obtain within their communities. Many of the participants reported that they were initially reliant on “word-of-mouth” referrals from friends and relatives in order to access medical care and social services when they arrived in King County. They also noted that they prefer to receive information about services from peers who are both linguistically and culturally attuned to their needs.

*“There’s a lot of people from other countries that need help and don’t know how to get it because they are afraid of Immigration. If HIV can’t be passed so easily, why have so many immigrants never been able to see their own family because they cannot come back to the USA? Americans can go and come back to many places. Why can’t illegals do the same?”*  
(Latino male PLWH)

Latino/as were also significantly more likely than white PLWH to prioritize emergency financial assistance (48% to 27%), insurance programs (52% versus 39%) and legal assistance (27% versus 14%). Providers noted that the primary legal need for their clients is for immigration assistance. They reported that many recently-arrived clients may not understand that services are available to assist them with immigration issues, and may believe that any contact with the legal system will lead to other services being denied them.

American Indian/Alaska Natives: In general, the limited number of American Indian survey respondents identified similar service priorities as other consumer sub-populations. These included housing assistance, peer emotional support, case management, and client advocacy. Although American Indian respondents were just as likely as other consumers to be accessing medical care, they were significantly less likely than other PLWH to prioritize this service, with only three of the fourteen respondents listing primary care as a service priority. Focus group participants stated that they each knew other HIV+ American Indians who were not seeking medical care for their HIV, due to distrust in the system or denial about the severity of their illness.

*“For some people, look at how much they’ve got going on besides HIV: they’re hungry, they need a place to sleep, they look for drugs and alcohol. They don’t have time for health. I know myself, I’d only go [for medical care] if I was really sick. For me, I didn’t go until I had abscesses.”* (Female American Indian PLWH)

Providers of services to American Indians and Alaska Natives noted that case management and client advocacy were extremely important for their clients. Most of their clients are dually or triply diagnosed (HIV, mental illness and chemical dependency), as well as needing assistance with housing, financial and insurance issues. As a result, these clients require more time and resources than other clients in order to help them access and maintain services.

Asian/Pacific Islanders: The limited number of Asian/Pacific Islander PWLH identified similar service priorities as other consumer sub-populations. The top service priority identified by A/PI PLWH was ambulatory care, followed by drug prescription programs, case management and insurance programs.

*“It’s so hard to say what’s important to me. All of the services are important for me!”  
(Female Asian/Pacific Islander PLWH)*

Only one of the thirteen A/PI respondents identified peer emotional support as a priority. Providers have noted that peer support is particularly difficult to generate in the A/PI PLWH community, due to the wide range of languages spoken and confidentiality concerns about being identified as HIV+ in small and relatively tight-knit communities.

In particular, providers stressed the importance of delivering services in a culturally competent manner, which takes into account the client’s culture of origin. Because the range of languages spoken in the Asian/Pacific Islander communities is extensive, this requires that providers have access to a broad range of Asian language interpreters.

#### 4. Service Gaps

African-Americans: African-American survey respondents were similar to other populations in their identification of service gaps. African-American PLWH ranked emergency financial assistance, housing assistance, client advocacy, counseling (peer emotional support) and food/meal programs among their top five service gaps (Table 33). Within the client advocacy category, African-Americans noted particular gaps in benefits counseling (10%) and peer or client advocacy (10%). Within the counseling category, the largest gap emerged in one-on-one peer support (18%).

In 1999, African-American PLWH were significantly more likely than whites to identify gaps in almost a third of all categories. In 2001, this disparity seems to have decreased in most areas. The only categories in which African-American consumers identified significantly greater gaps than whites are case management (11% versus 3%) and food/meal programs (16% versus 8%). As one provider of services to African-American PLWH noted, “Clients may complain about problems with quality and services [in food programs], but no one is going hungry. The issue may be the type of food offered.”

Both providers and consumers voiced concerns about the lack of African-American case managers in the King County Continuum of Care. Several clients noted that, while they appreciate the services their case manager has provided, they do not feel the same sort of bond with their case managers as described by other consumers. White case managers may not be well acquainted with African-American culture, and may not respond well to different communication styles. As a result, African-American clients may be more reliant on assistance from peer advocates than other populations.

**Table 33. Service Gaps: African-Americans (n=62)**

RANK	SERVICE	# OF VOTES	% OF RESP.
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1	Direct emergency financial assistance	15	24%
2	Housing assistance/related services	13	21%
3 (tie)	Client advocacy	12	19%
3 (tie)	Counseling (emotional support)	12	19%
5	Food/meals	10	16%
6	Alternative, non-Western therapies	9	15%
7	Case management	7	11%
8	Referral	6	10%
9 (tie)	Adult day health	5	8%
9 (tie)	Dental care	5	8%

Interpreter services emerged as a major gap for African immigrant PLWH. Because these are relatively new populations to emerge among the HIV cases in King County, the pool of available interpreters who speak Amharic, Somali and other West African languages is more limited than for other linguistic minorities. Additionally, concerns about confidentiality may lead clients to refuse to work with certain interpreters if those interpreters are closely connected with the client's community.

Finding appropriate legal assistance can also be challenging for providers working with the refugee population. The legal issues surrounding re-location to the United States are complex, and made more difficult due to HIV status. Providers also noted that identifying culturally-appropriate food and meal programs for their African clients is very difficult.

Latino/Latinas: Consistent with rankings from the 1999 needs assessment, Latino/a survey respondents ranked emergency financial assistance as the largest service gap in the Continuum of Care, followed by counseling (emotional support), housing assistance, client advocacy and legal assistance (Table 34). Latino/Latino consumers were significantly more likely than whites to report gaps in over half of all service categories.

**Table 34. Service Gaps: Latino/Latinas (n=52)**

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Direct emergency financial assistance	20	38%
2	Counseling (emotional support )	19	37%
3	Housing assistance/related services	18	35%
4	Client advocacy	17	33%
5	Legal assistance	15	29%
6	Adult day health	14	27%
7	Alternative, non-Western therapies	13	25%
8	Dental care	12	23%
9	Referral	11	21%

10	Food/meals	10	19%
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The largest disparity between Latino/a and white PLWH emerged in the category of adult day health, with 27% of Latinos/as reporting a service gap versus 2% of whites. Although the provider agency of adult day health services has increased the number of Spanish-speaking staff in recent years (and reported an increase in Spanish-speaking clients), clients may still feel uncomfortable in social and therapeutic settings which are primarily Anglo. One provider noted that several of her clients have experienced improved health and no longer meet the medical criteria necessary to qualify for the program.

Other major gap disparities between Latino/as and white PLWH exist the in the categories of counseling (emotional support) (37% versus 17%), housing assistance (35% versus 16%), legal assistance (29% versus 8%) and client advocacy (33% versus 18%). In most cases, focus group participants pointed to language and cultural barriers that prevented them and their peers from fully accessing these services. Providers noted that their clients may individually express a desire for peer support (particularly support groups), but are unlikely to participate in group support activities. As previously noted, immigration and language issues contribute to the gap in housing assistance and legal services.

As in previous assessments, access to Spanish-speaking providers was also identified as a service gap across the continuum of HIV services. Focus group participants who were not proficient in English expressed a desire to have services provided in their native language, rather than through an interpreter. They noted that it is rare to find more than one or two Spanish-speaking staff at agencies, but acknowledged that progress is being made. Additionally, several focus group participants called attention to the scarcity of culturally competent Spanish-speaking case managers. They noted that having a case manager who is bilingual is not enough to ensure that effective communication occurs between provider and client. As a result, several participants stated that they felt that they were not given sufficient information about available services and eligibility requirements.

American Indian/Alaska Natives: Peer emotional support and housing assistance emerged as the largest service gaps among American Indian PLWH. Focus group participants identified concerns that one-on-one and group support was not available to them. They expressed frustration that no groups existed specific to the needs of American Indians living with HIV, since the termination of the support group at the Seattle Indian Health Board. They felt that HIV/AIDS agencies serving persons of color do not seem to be as inclusive of American Indians as other populations and that mainstream HIV/AIDS organizations target their services to gay, white men.

Participants expressed dissatisfaction with lengthy waiting lists and lack of affordable housing options. Many of the participants have had transient housing arrangements, moving in and out of Seattle and other parts of King County. Several have returned to the reservation for periods of time, but stated that they were worried about news of their HIV status becoming public in their community. As a result, participants tend to “couch surf” with families and friends in the absence of long-term housing arrangements. Providers noted that client histories of substance use and incarceration also contribute to the difficulty in accessing permanent housing.



Asian/Pacific Islanders: Due to the small number of surveys returned from A/PI consumers, no patterns emerged regarding identifying service gaps. No service was listed as a gap by more than three of the thirteen A/PI respondents.

As with Latinos and American Indians, providers stated that service gaps were largely dependent on the degree of integration into the mainstream culture exhibited by their clients. For clients who are familiar with and comfortable using mainstream HIV/AIDS services, few gaps exist. However, for those who are recent immigrants or for whom English is not their first language, obtaining medical information about HIV can be difficult. Clients have stated that their doctors may not have the time to discuss their treatment and provide information on HIV/AIDS that is fully comprehensible to them. It is also rare that written materials are translated into the large number of Asian languages spoken in King County, which also limits consumer knowledge about the disease, treatments, and available services.

Providers also noted gaps in access to culturally-specific food and meal programs and immigration advocacy. Due to the low numbers of A/PI PLWH, agencies may not be able to devote specific resources to Asian groceries and meals. One provider suggested expanding the grocery voucher program to include Uwajimaya, a grocery and retail store in the International District in Seattle. Immigration issues can be very complex and anxiety-ridden for non-resident HIV+ PLWH, but obtaining legal assistance from professionals who are familiar with both HIV issues and the client's culture of origin is difficult.

## **5. Access Barriers**

African-Americans: In general, African-American survey respondents reported similar access barriers as other populations. The most common barrier identified by African-American PLWH is lack of information about available services (Table 35). Although inability to afford needed services was the second most common barrier identified by African-American consumers, African-Americans were significantly less likely than whites to report financial barriers (10% versus 21%). This may be due to differences in average annual incomes, as a higher percentage of African-American consumers appear to qualify for Ryan White-funded programs than do whites.

Despite the fact that none of the African-American survey respondents reported that poor service quality was an access barrier, this was the major concern expressed by participants in the African-American focus group regarding several services. In particular, several focus group members stated dissatisfaction with the quality of medical care, case management, financial assistance and insurance programs they had received.

**Table 35. Access Barriers: African-Americans (n=62)**

<b>BARRIER</b>	<b># OF VOTES</b>	<b>% OF RESP.</b>
Lack of information	16	26%
Financial (can't afford it)	6	10%
Haven't asked	5	8%
Eligibility (based on financial status)	4	6%

Waiting list; not enough services	4	6%
Conflicts with schedule	4	6%

Providers of services to African-American clients echoed these sentiments. Providers reported that several of their clients feel that they have been denied services because of their race, or that the services they have gotten are inferior to those given white PLWH. As in previous years, providers and focus group participants reported that African-American PLWH are generally less connected to the overall service system, and have unequal access to information about available services and how decisions about eligibility are determined.

Providers also noted that convincing clients of the importance of consistent, ongoing medical care is a challenge for them. This is particularly true of very low income clients and those with substance use backgrounds. Medical care often does not assume a priority in these clients' lives, and the provider needs to help the client realize that a commitment to ongoing care is necessary.

As previously noted, language differences are the primary access barrier for the population of African immigrant PLWH. Not only is it difficult to find providers and interpreters who speak the various West African languages necessary to serve this population, but information and materials about HIV are generally unavailable as well.

Providers noted that cultural stigma surrounding HIV is a very difficult barrier to overcome. In some cases, husbands and wives have not even told each other about their HIV status. As a result, clients can be very isolated, even within their own communities. Due to language and cultural barriers, access to support from the broader PLWH population is rarely possible. This often entails case managers having to make more frequent home visits than with other clients, since the client may be afraid to be seen in a clinical or social service setting associated with HIV.

Latino/Latinas: Latino and Latina respondents to the consumer survey expressed similar access barriers as other populations. No statistically significant differences emerged in the types of access barriers identified by Latino/a survey respondents versus those identified by other populations (Table 36).

**Table 36. Access Barriers: Latinos/Latinas (n=52)**

BARRIER	# OF VOTES	% OF RESP.
Lack of information	15	29%
Eligibility (non-specific)	4	8%
Financial (can't afford it)	3	6%
Language barriers	3	6%
Waiting list; not enough services	3	6%
Eligibility (based on disability status)	3	6%

Based on information from focus group participants and service providers, cultural and linguistic differences continue to be significant barriers for Latino/a PLWH. Providers and consumers noted the importance of understanding Latino cultural norms in order to be able to offer culturally sensitive services to this population. These norms include the high value placed on family, the importance of religion, and cultural norms against talking directly about sex and sexuality. This is particularly true of clients who are recent arrivals to the United States, and may be having trouble adjusting to the dominant culture.

*“When a person speaks Spanish, but inside is an English-speaking person trying to say something from Spanish to English, they can turn one word around and change the whole meaning of a sentence. It is very frustrating for all of us to get through to someone, knowing that person has said something you didn’t say. Services are so difficult for us to access because of the fact that we can’t find someone who is Latino – not just an American who speaks Spanish.” (Latino male PLWH, native Spanish speaker)*

Language barriers continue to exist for the growing numbers of clients who have limited or no English proficiency. Providers noted that some clients might be ashamed to admit that they cannot understand English, and may sit through appointments without having actually comprehended what was being discussed. Focus group participants noted that they feel cut off from much of the information that is available to English-speaking PLWH, particularly if they are unfamiliar with the ways in which services are provided in King County as opposed to their country of origin.

Providers noted that disclosure and confidentiality may be major issues for their clients, especially for those who are new to the country or newly diagnosed. If clients are undocumented or fearful of being deported due to their HIV status, they may be unwilling to seek services. They may be fearful of bureaucracy and resistant to filling out forms at service agencies that identify them as HIV+ and/or as without legal standing.

Latino/a PLWH may also experience extreme feelings of isolation. As one provider noted, “HIV has alienated clients from their country, their family, and their community. The new culture is very difficult to adopt, leaving them with a ‘floating feeling,’ like they don’t belong anywhere.” Many clients have not shared their sexual history or their HIV status with their close friends or family. Additionally, if Latino male clients are not gay-identified, they may feel uncomfortable in group settings or at agencies that they perceive as gay-oriented.

American Indian/Alaska Natives: Providers and focus group participants identified lack of Indian-specific programs and cultural barriers at mainstream agencies. Due to historical persecution and disenfranchisement, many American Indian clients lack trust in mainstream agencies and providers. Mainstream providers may lack sensitivity to American Indian spiritual concepts, family/kinship systems, and communication styles.

*“We all basically know each other. If we don’t know somebody by name, we know their cousins and family. If you go knocking on the door, their uncles and aunts are sitting there. Other family members will want to know. They’ll just shut the door and be shamed. They’ll be like, “No! Nobody has it here!” (American Indian female PLWH)*

Focus group participants noted that internal cultural barriers may inhibit American Indians from accessing HIV care and services. They stated that issues of shame, fear and rejection may keep Indian PLWH from reaching out for help in their community. As a result, outreach and prevention education on reservations is very difficult. If Indians leave the reservation to seek services, they are often unaware of available resources and may not know where to turn for assistance.

Providers also noted that many of their clients are homeless, and experience all of the access barriers related to not having a permanent residence. These include difficulty in maintaining contact with case managers and other service providers, unsanitary living conditions, inability to attend to matters of basic hygiene, and lack of space to store and/or refrigerate medications.

Asian/Pacific Islanders: Providers of services to Asian/Pacific Islander PLWH identified many of the same access barriers as providers of service to Latinos, with cultural and language barriers being most significant. Cultural norms about disease and treatment may inhibit clients from seeking services and/or complying with medication regimens unless they are very ill.

One provider noted that “the system lumps all Asians and Pacific Islanders together.” In reality, providers must recognize that cultural norms, health beliefs and treatment systems differ between the various Asian and Pacific Islander communities. Assuming that all A/PI clients share common values and attitudes can undermine provider attempts to effectively communicate with and serve their clients.

Providers suggested several solutions for overcoming access barriers for PLWH of color:

- Be more aware of cultural diversity and sensitivity issues in all settings. This includes increasing the number of providers who are persons of color, developing more effective and consistent linkages between the HIV care system and other agencies that target communities of color, and providing information and training to mainstream providers about how to better serve their clients of color. Several providers noted that models for technical assistance in these areas exist in other states (such as California and Florida) and that the King County Continuum of Care should take advantage of the expertise developed in other parts of the country.
- Develop and/or expand peer support programs for PLWH of color. Persons of color who discover that they are HIV+ may not immediately want to involve themselves in the mainstream medical and social service systems. They would benefit from meeting other members of their communities who share their language and belief systems and who can help them understand the system. This will ultimately help mainstream providers, as peer advocates can help provide linkages to the system and allay fears or suspicions on the part of new clients.
- Develop improved outreach strategies to provide information and education about HIV/AIDS and available services in ethnic communities. Do not assume that communities of color (and providers within these communities) are as knowledgeable about the HIV/AIDS Continuum

of Care as the majority of gay white male clients. Service providers may need to go into the community and identify potential clients, as opposed to waiting for clients to come to them.

- Make medical and social service appointments more flexible to acknowledge different concepts of time and access issues in non-white populations.
- Improve the capacity of agencies serving persons of color to provide more effective HIV-related services. This includes the provision of technical assistance as well as increased funding for these agencies.
- Whenever possible, hire staff who are bi-cultural, rather than merely bi-lingual.
- Educate case managers about immigration issues. Ensure that linkages exist between HIV service providers and legal experts who understand the complex issues regarding relocation and re-settlement.
- Ensure that staff at key service access points (counseling and testing sites, community clinics, case management agencies) have easy access to interpreters. Ensure that agencies earmark funding for interpreter services in their program budgets.
- Ensure that non-English language written materials are readily available, culturally sensitive, and created to effectively address persons with limited reading skills.



## D. Women

*"I was diagnosed at [a community clinic]. The woman said, "Why do you need to worry about HIV?" They went ahead and cured my yeast infection. Then they sat me down in a conference room and said, "You're HIV+." I got the news from the receptionist." (White female PLWH)*

### 1. Epidemiologic Profile

In King County, women represent a relatively small proportion of the total HIV infections and AIDS cases. However, the proportion of cases in women has increased in recent years, a trend that is expected to continue. Women with HIV/AIDS tend to be younger than men, and are significantly more likely to have acquired HIV through heterosexual contact. Women of color are disproportionately affected.

Status and trends in AIDS cases: Through 6/30/01, there have been 318 cumulative AIDS cases diagnosed in King County females. AIDS cases in women have risen from fewer than ten cases per year in the 1980's to a peak of 35 cases in 1995. Since 1995, the number of women diagnosed with AIDS in King County has decreased slightly or remained constant. However, the proportion of all reported cases that are women has risen consistently from 1-2% of cases in the 1980's to 10-12% in recent years.

Nearly half (47%) of women with AIDS in King County were reported as having acquired HIV through heterosexual contact, 31% through use of injection drugs, 7% by blood transfusion, and 16% by undetermined exposure. In King County, the rate of AIDS among African American and American Indian/Alaska Native women is over ten times higher than in white women and the rate among Latinas is twice that of white women.

Population sizes: In King County, for 2001 the total female population is approximately 906,700. The estimated number of women who are drug injectors or sex partners of injectors is 9,000. The total estimated number of HIV positive women in King County is between 350 to 550.

HIV seroprevalence: In the Survey of Childbearing Women in King County, conducted from 1989 to 1995, 0.04% of the over 123,000 women tested were HIV positive. Among women tested at the King County Sexually Transmitted Disease (STD) Clinic in 1988-1999, 0.3% tested positive, while 1.4% of women tested at drug treatment centers during the same time frame were HIV positive.

### 2. Service Trends

Demographic trends related to female consumers continue along similar lines as noted in the past two needs assessments. Providers in almost all service categories reported increases in the numbers of women accessing services. Providers noted that the population of women with HIV is growing older, with the majority of clients in their 30's and 40's. Increasing numbers of younger women are also seeking services, especially adolescent girls between the ages of 16 and 21, several of whom are pregnant.

Heterosexual transmission remains the main transmission risk reported by clients. Self-reported injection drug use-related transmission has declined somewhat, but providers note that it is often difficult to distinguish between IDU transmission and transmission due to sexual contact with male IDU's.

As reported in previous years, King County providers are seeing female clients from across the state of Washington. Although most King County female PLWH are Seattle residents, providers are seeing growing numbers of their female clients relocating to South King County due to financial pressures, as well as small increases in the number of female clients living in East King County. Providers also noted that they are seeing an increase in homeless female PLWH, particularly among Latina and American Indian women.

Providers report that the overwhelming majority of their female clients are living at or near the poverty level, particularly those with dependent children. Most of these clients rely on government-supported medical care and financial assistance, much of which has been accessed through their children's coverage. A growing number of low-income female PLWH are involved in the "Welfare to Work" program, but in many case these women are scheduled to run up against their time-limited eligibility.

Service providers report that high percentages of their female clients are multiply diagnosed (HIV, mental illness and/or chemical dependency). Providers of services to women report that upwards of 60% of their female PLWH caseloads have been diagnosed with some form of mental illness, with depression being the most common disorder. Diagnoses of schizophrenia and bipolar disorder are also increasing in this population. Twenty-nine percent of female survey respondents reported that they had been diagnosed with mental illness.

Substance use continues to have a significant impact on the lives of female PLWH. Providers noted that over half of their female clients have histories of substance abuse. Multi-drug use is prevalent, particularly crack cocaine and heroin. More clients are now enrolled in methadone treatment and harm reduction services, in general. Providers noted, however, that progress within the "Welfare to Work" program is often complicated by treatment recovery activities.

Consistent with epidemiologic trends and recent assessment reports, service providers who work with HIV+ women note that a high proportion of their client caseloads are women of color. Providers report that they are seeing increasing numbers of women from all racial categories, particularly African-Americans, Latinas and American Indian women. During the past two years, providers noted that women from the growing refugee populations in King County are beginning to utilize services after ongoing attempts to engage them.

As noted in previous assessment reports, female survey respondents were statistically less likely than males to have received AIDS diagnoses (38% versus 57%). Women were also significantly more likely to report T-cell counts above 200. However, service providers report seeing increases in the number of women presenting with HIV-related symptoms, rising numbers of HIV-related deaths and increasing failures with HIV medications. As one provider noted, "Women are not getting enough medical care." In many cases, these women have relied on generalists or OB/GYN's for their care, and these providers may have failed to diagnose HIV-related symptoms until the women have progressed far into their illness.

"I have Medicaid and Medicare insurance. Every time I want my medication, I have trouble with my spend-down. The first of the month, I am on spend-down. And about every six months, I cannot get my medication. They lose paperwork, or give you some other excuse. So then I have to go out and try to spend \$700 worth of stuff with the government so I can get my medications." (African-American female PLWH)



Providers noted that their female clients have had relatively few access problems with HIV medications. This sentiment was echoed among female focus group participants. However, both providers and consumers reported complex adherence issues. These include lack of trust in the medications (several focus group participants referred to antiretroviral therapy as “poison”), unstable housing and living situations, and mental health and chemical dependency barriers. Additionally, women of color and female immigrants may face cultural challenges interacting with the medical system. As a result, the gap between male and female PLWH has widened in the past two years regarding current medication status. Female survey respondents remain significantly less likely than males to be on antiviral medications (59% versus 82%), protease inhibitors (31% versus 57%) and drugs to treat or prevent opportunistic infections (27% versus 45%).

Providers of services to women noted that their clients are utilizing a wider array of services from across the Continuum of Care, including medical care. Nevertheless, based on responses to the 2001 consumer survey, female PLWH were slightly less likely to use several key services than male PLWH. Women were slightly less likely than men to use primary care (89% versus 95%), the Washington State AIDS Prescription Drug Program (42% versus 55%), and health insurance continuation programs (47% versus 59%). Women were also less likely than men to use case management (67% versus 81%), despite information from women in focus groups about the vital importance of case managers in helping them access needed services. Women were equally as likely as men to use mental health therapy (47% versus 48%). Although women were no more likely than men to report using injection and/or other street drugs, they were significantly more likely than men to report receiving substance use counseling (25% versus 15%).

### 3. Service Priorities

Female survey respondents ranked housing assistance and related services as their number one service priority (Table 37). Client advocacy tied with case management as the second most-frequently mentioned priority, followed by primary medical care, counseling (emotional support) and dental care.

Reversing a trend observed in 1997 and 1999, female and male PLWH reported several significant differences in service prioritization. Women were significantly more likely than men to prioritize housing services (60% versus 45%), client advocacy (particularly peer advocacy) (50% versus 33%), and counseling (emotional support) (40% versus 26%). Conversely, women were significantly less likely than men to prioritize clinical services, such as medical care (43% versus 67%), dental care (39% versus 58%) and drug prescription programs (29% versus 41%).

**Table 37. Service Priorities: Women (n=72; 3 missing responses)**

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Housing assistance/related services	43	60%
2 (tie)	Client advocacy	36	50%
2 (tie)	Case management	36	50%
4	Ambulatory/outpatient medical care	31	43%
5	Counseling (emotional support)	29	40%

6	Dental care	28	39%
7 (tie)	Direct emergency financial assistance	26	36%
7 (tie)	Insurance programs	26	36%
9	Food/meals	23	32%
10	Drug prescription program	21	29%

As noted by providers, the population of women with HIV is geographically more dispersed than males, and less likely to reside close to the core of services located in central Seattle. As a result, women exhibit greater transportation needs in order to access most services. Female PLWH rated peer emotional support significantly higher than males, based largely on reported feelings of isolation and lack of information about available services. Focus group participants and providers themselves noted that peer support services are vital for women not only for the emotional support they receive, but for the provision of informal access linkages to treatment information, medical care and social services.

#### 4. Service Gaps

Female survey respondents were similar to other populations in their ranking of service gaps. Women ranked direct emergency financial assistance, housing assistance and related services, client advocacy (particularly access to medical information specific to women's health issues), food/meals and alternative, non-Western therapies among their top five service gaps (Table 38).

In comparison to previous surveys, differences in service access based on gender were reported in very few service categories. However, 32% of female respondents noted difficulty in accessing emergency financial assistance, as compared to 22% of males. Women were also more likely than men to identify gaps in housing assistance and related services (25% versus 18%) and in food and meal programs (21% versus 8%).

*“Even with all the services that are available now, I find I can’t manage on my monthly SSDI check. Making the transition back to work is stressful and I need more support and services to get me back on my feet again. It’s hard to socialize and interact when you’re not even financially breaking even.” (White female PLWH)*

**Table 38. Service Gaps: Women (n=75)**

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Direct emergency financial assistance	24	32%
2	Housing assistance/related services	19	25%
3	Client advocacy	18	24%
4 (tie)	Food/meals	16	21%
4 (tie)	Alternative/non-Western therapies	16	21%
6	Counseling (emotional support)	14	19%
7	Dental care	10	13%
8 (tie)	Case management	9	12%

8 (tie)	Mental health therapy/counseling	9	12%
10	Legal assistance	8	11%

**One key finding on the 2001 survey was that women of color exhibited greater access gaps than white female PLWH in almost all service categories. Female PLWH of color were almost three times as likely as white females to identify gaps in access to case management (17% versus 6%), noting that very few case managers of color were available in the Continuum to assist them. Women of color were also more likely than white women to identify gaps in housing assistance (29% versus 19%), legal assistance (14% versus 6%), dental care (17% versus 10%), food/meals (31% versus 10%), and peer counseling/emotional support (24% versus 13%). Latinas, in particular, were more likely to identify service gaps, based largely on language barriers and concerns about confidentiality.**

Providers were in agreement regarding the gap in financial services available to women. In particular, providers noted that funds seem to be diminishing to assist their clients in paying rent and utilities and managing transportation expenses. The processes by which clients access these funds also continue to become more restrictive and complex than in past years, making it difficult for women to negotiate the various systems that administer financial assistance programs.

Other services which providers identified as gaps for their female clients include housing, transportation and child care. Providers expressed ongoing concerns that there are few housing options for women with dependent children, and that available options are often located far from core medical services.

Very few female survey respondents reported a gap in primary care access (only 3 out of 75 female PLWH stated that they needed, but could not get medical care). However, providers noted that utilization of medical services, not access to these services, is the challenge for their clients. Reasons for this situation are outlined below, under “Access Barriers.”

## 5. Access Barriers

On the 2001 consumer survey, female consumers identified lack of information as the key access barrier to services (Table 39). Women in focus groups also noted that, prior to accessing HIV-related medical care and case management, they were relatively unaware of services within the HIV system. Many stated that it was only through meeting other women living with HIV that they developed any sense of knowledge about the spectrum of services at their disposal. As noted by one service provider, “Women are a ‘population,’ not a community.” This is particularly true when compared to gay/bisexual men who have a built-in community to service their support and information needs. As a result, peer advocacy and support groups assume a vital role in service access for female PLWH.

**Table 39. Access Barriers: Women (n=75)**

BARRIER	# OF VOTES	% OF RESP.
Lack of information	22	29%
Financial (can't afford)	12	16%
Geography (live too far away)	6	8%
Conflicts with schedule	6	8%
Haven't asked	5	7%
Waiting list/availability	5	7%

***“We have so many different needs. It seems as if the whole of HIV has been based around the male person. From the amount of medicine the doctors consider therapeutic to the kinds of services available. What’s up? Can we start making it more woman and family friendly?” (American Indian female PLWH)***

Providers of services to women noted that histories of mental illness and chemical dependency are major barriers to their clients’ ability to access services, and that many of the consumers they see come from abusive families and/or partner situations. Several providers pointed to general “life chaos” for their female clients, describing the complex issues surrounding poverty, parenthood, lack of education, and lack of social support, all of which make attention to personal health care more difficult.

It should also be noted that, as in previous years, female consumers and providers alike reiterated that women often defer to the needs of family members rather than accessing care themselves. Given the high percentage of female survey respondents who report having dependent children (37%), it is likely that many of the HIV+ women who are not receiving medical care have refrained from accessing care due to family obligations. Improvements in child care access, transportation for families, and housing options for families may be necessary to help these women obtain and maintain primary care.

Several focus group participants noted concerns about confidentiality as a barrier to their trust in receiving services. They may feel the need to hide their diagnoses from co-workers, family members (especially children) and their traditional support systems (e.g., church communities, school groups, etc.). In general, consumers reported feeling more social stigma about their HIV status than men.

Despite these access barriers, focus group participants did note unanimously that the service system for women has improved dramatically over the past decade. As one participant noted, “I get into the system easier than guys.” As more and more services have been developed that focus specifically on women’s needs, the key issue appears to be integrating women initially into the system and maintaining their engagement, rather than a lack of available services. Providers and consumers offered the following suggestions about how to improve service delivery and access for women living with HIV/AIDS:

- Develop increased flexibility around appointments, both in terms of time and location. Due to family and other time demands, women are not always able to come to their appointments when they are scheduled. If a client arrives late, try to ensure that she can still keep her appointment, if at all possible.
- Address the increasing demand for affordable housing for families. Explore ways to increase housing options for women with HIV who have dependent children.
- Provide accessible and available transportation for women and their families, not only to medical appointments, but to other important services.
- Expand access to childcare services. This includes both onsite care available at clinics and agencies, but off-site child care resources that are responsive to emergent needs.
- Acknowledge the intrinsic and ever-growing relationship between domestic violence and HIV status. Providers report that many of their female clients come from histories or current situations of domestic violence. However, most domestic violence agencies are ill-equipped to deal with HIV-related issues and HIV providers are frequently uneducated on domestic violence and its consequences. Linkages and cross-trainings between these systems are vital.
- Develop awareness among the service provider community of cultural issues as they specifically relate to female PLWH. This extends beyond simple language differences, to include understanding about family dynamics, education, the role of women in various cultures and the ways in which women of various backgrounds understand and access the medical system.

## E. East and South King County Residents

“People in South County are scared. You don’t want to walk around talking about the fact that you’ve got AIDS. Most of the people I’ve talked to live down here to get away from the city. For some people, it’s actually physically painful to ride the bus. Having just one little satellite thing down here which had a clinic and support group-type thing would be great.”  
(Male PLWH, South King County)

### 1. Epidemiologic Profile

Of the 6,096 cumulative King County AIDS cases reported through the end of 2000, 82% were diagnosed in Seattle, 16% were living in other areas of the county and 2% had no known zip code at time of diagnosis (Table 40). Of the non-Seattle cases, 61% were residents of South King County, 37% were from the Eastside and 2% from Vashon Island.

**Table 40. Demographic characteristics by residence of cumulative King County AIDS cases through 12/00**

	City of Seattle		KC, Outside Seattle		Unknown	
	Number	%	Number	%	Number	%
<b>SEX</b>						
Male	4,793	(96)	902	(90)	108	(94)
Female	191	(4)	95	(10)	7	(6)
<b>RACE/ETHNICITY</b>						
White	3,999	(80)	788	(79)	95	(83)
Black	509	(10)	112	(11)	11	(10)
Latino/Latina	298	(6)	69	(7)	7	(6)
Asian/Pacific Islander	96	(2)	19	(2)	2	(2)
Am. Indian/AK Native	82	(2)	9	(1)	0	(0)
<b>EXPOSURE</b>						
Male/male sex	3,862	(77)	662	(66)	76	(66)
Injection drug use (IDU)	264	(5)	75	(8)	7	(6)
IDU & male/male sex	538	(11)	74	(7)	11	(10)
Heterosexual contact	116	(2)	69	(7)	9	(8)
Undetermined/Other	204	(4)	117	(12)	12	(10)
<b>TOTAL CASES</b>	<b>4,984</b>	<b>(82)</b>	<b>997</b>	<b>(16)</b>	<b>115</b>	<b>(2)</b>

Since named HIV reporting began in King County in 9/99, 220 people with non-AIDS HIV infection have been newly diagnosed. Of these, 76% were residents of Seattle, 21% lived outside of Seattle and 2% had an unknown residence at time of diagnosis. These HIV cases represent persons with more recent diagnoses compared with AIDS case report data and suggest that the proportion of new HIV infections is increasing outside of Seattle.

Compared to Seattle residents reported with AIDS, those living in other areas of King County were more likely to be female (10% versus 4%) and to have been reported as infected with HIV either heterosexually (7% versus 2%) or through non-MSM injection drug use (8% versus 5%).

### 2. Service Trends

As in previous years, East and South King County providers reported that a large majority of their clients were white and self-identified as gay. Despite the fact the non-Seattle PLWH are more likely to be female, providers noted that the number of female PLWH on their caseloads continues to decrease, as more female clients living outside Seattle prefer to receive services from Seattle-based providers and agencies. This discrepancy was noticeable among female focus group participants, many of whom reside outside of Seattle, but receive services in the city.

Reversing a trend from previous years, non-Seattle providers reported that they have seen fewer PLWH of color in the past two years. Although South County providers noted a small increase in the number of Latinos on their caseloads, all non-Seattle providers noted seeing fewer African-Americans and PLWH of other races. They attribute this to reasons similar to the decrease in female clients, as clients of color have become more familiar with Seattle-based services and are willing to travel to the city for their care and ancillary support.

Another change from recent years is the increase in self-identified gay and bisexual men receiving services in South and East King County. In prior years, providers reported seeing many clients who denied MSM transmission, or who were not “out” about their sexual orientation and behaviors to their family or community. Although this continues to be an issue for many non-Seattle PLWH, the numbers seem to be decreasing.

Non-Seattle consumers represent a diverse socioeconomic range, although East Side providers noted a higher proportion of their clientele who are earning over \$40,000 than was reported by Seattle or South King County providers. South County clients are primarily middle to lower middle class. In both sub-populations, many consumers are now living at or below the poverty level due to AIDS-related disability. For those who are not yet disabled, many are caught in a double bind: their incomes are insufficient to cover the services they need, but exceed Medicaid and/or Ryan White income eligibility limits.

“I would love to see an occasional potluck for people with HIV/AIDS. A place where we could meet each other. It’s very frustrating living on the Eastside, and having case managers change hands. It seems I just have a rapport with one and someone else is put in charge. The only reason I don’t quit is that I need the services, which outweighs the frustration.” (MSM PLWH, East King County)

As noted previously, East and South King County providers report that most of their clients travel to Seattle to access non-medical services. For many services, such as emotional support, mental health counseling, and dental care, there may be few, if any, options available to non-Seattle PLWH in their place of residence. Because East and South King County consumers may not be “out” about their HIV status to others in their communities, consumers may not access support services in their place of residence for fear of being identified as living with HIV/AIDS.

In general, providers report that clients’ health has fluctuated in the past few years. Providers have seen an increase in clients with symptomatic HIV infection, and more deaths than in recent years. In prior surveys, significantly higher percentages of East and South County respondents reported living with HIV, non-AIDS than Seattle residents. However, the percent of consumers who reported AIDS diagnoses were almost equal for all geographic areas: East County (51% of consumers reported receiving an AIDS diagnosis), South County (53%) and Seattle (53%).

Providers report that East and South King County PLWH have good access to prescription medications. Providers estimate that a large majority of their clients are adherent to drug regimens, although South County providers noted that clients require a greater degree of medication management than East County PLWH. South County survey respondents reported higher levels of adherence problems (37% reporting difficulty in taking medications as prescribed) than did Seattle residents (31%) or PLWH in East County (23%).

East and South King County survey respondents were also significantly less likely than Seattle residents to report co-morbidities. Thirty-four percent of Seattle respondents reported being diagnosed with some form of mental illness, versus 25% of South KC respondents and only 12% of East KC respondents. However, providers of services to non-Seattle PLWH noted that over half the clients on their caseload have mental health issues, either diagnosed or undiagnosed, with many suffering from clinical depression. They noted that their clients are not accessing mental health services despite their suggestions and referrals.

Non-Seattle survey respondents reported comparable levels of substance use as Seattle residents. This contradicts epidemiologic data that suggests higher levels of non-MSM IDU-related HIV transmission among non-Seattle PLWH. Providers noted that substance use among their East and South County clients is more likely to be hidden than among Seattle clients, because the population of active drug users is smaller and more clandestine than in the city.

In prior years, a significantly lower percentage of South and East King County consumers reported currently accessing primary care than did Seattle residents (84% versus 94%, on the 1999 consumer survey). Although non-Seattle survey respondents in 2001 reported higher rates of primary care utilization rates than in previous years, the percentage is still lower than that for Seattle consumers (91% versus 96%). Non-Seattle consumers were no more likely than Seattle residents to report being unable to obtain medical care (only 1% of each population stated that they could not access needed medical care). Based on information from South and East King County focus group participants and from provider interviews, it appears that non-Seattle residents may be less likely to actively pursue ongoing medical monitoring, unless symptoms or medication side effects are present. This may be related to fears about confidentiality and disclosure (having to take time off from work and/or explain to friends/colleagues about attending medical appointments) as well as geographic barriers such as traveling into Seattle to attend appointments.

In past years, South and East KC PLWH reported significantly lower utilization rates in several other Ryan White service categories than their Seattle counterparts. However, due to recent Planning Council-applied funding caveats, and increased outreach activities by Seattle-based HIV service agencies, these disparities have lessened to a great degree in 2001. South and East King County PLWH exhibit greater or similar utilization rates to Seattle residents in many key service areas: insurance continuation programs (used by 64% of non-Seattle clients versus 55% of Seattle PLWH), AIDS drug assistance program (56% versus 52%), client advocacy, including information about HIV disease and therapies (86% versus 83%), case management (77% versus 80%), and dental care (68% versus 72%).



The sole service areas in which South and East King County PLWH survey respondents reported lower utilization rates were mental health therapy and counseling (39% versus 51%) and substance use treatment and counseling (5% versus 19%). This is consistent with survey responses that suggest that non-Seattle consumers are less likely to have been diagnosed with mental illness and less likely to have histories of substance use. Surprisingly, non-Seattle residents were no more likely than Seattle residents to use transportation services (32% each). Several focus group respondents noted that they continue to drive to Seattle for appointments even when they are feeling ill or weak, rather than rely on public or volunteer transportation assistance.

### 3. Service Priorities

East and South King County survey respondents identified service priorities which were fairly similar to the responses of the survey population as a whole (Table 41). Dental care emerged as the number one ranked priority, followed by primary medical care, insurance programs, case management and housing assistance and related services.

As in previous years, focus group participants highlighted case management as a vital service. This was particularly true of South County consumers, who noted that their case manager served as their primary link to care and support services. East County PLWH were somewhat less likely to prioritize case management services. Consumers who participated in the East County focus group had been living with HIV for quite a while, and felt more confident navigating the Continuum of Care themselves.

**Table 41. Service Priorities: East and South County Residents  
(n=98; 9 missing responses)**

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Dental care	65	66%
2	Ambulatory/outpatient medical care	57	58%
3	Insurance programs	51	52%
4 (tie)	Case management	41	42%
4 (tie)	Housing assistance/related services	41	42%
6	Drug prescription program (ADAP)	40	41%
7	Client advocacy	39	40%
8	Direct emergency financial assistance	29	30%
9 (tie)	Food/meals	27	28%
9 (tie)	Counseling (emotional support)	27	28%

As previously noted, place of residence did not appear to play a major factor in the ways in which consumers prioritized most services. This is particularly true for South County consumers, whose priority rankings and percentage response mirrored Seattle PLWH in almost all cases. However, East County PLWH were significantly more likely than Seattle or South County consumers to prioritize referral programs (29% versus 8% and 9%, respectively) and

alternative, non-Western therapies (39% versus 31% and 10%, respectively). East County consumers were also significantly less likely than other PLWH to prioritize primary medical care (46% versus 64% of Seattle PLWH and 63% of South County PLWH).

#### 4. Service Gaps

East and South King County survey respondents reported similar service gaps as other PLWH populations. The top five service gaps identified by non-Seattle consumers included direct emergency financial assistance, alternative therapies, counseling (emotional support), client advocacy and housing assistance (Table 42). With the exception of housing assistance, the four top ranked service gaps for 2001 are identical to those identified by East and South KC PLWH in 1999.

**Table 42. Service Gaps: East and South County Residents (n=107)**

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Direct emergency financial assistance	31	29%
2	Alternative, non-Western therapies	28	26%
3	Counseling (emotional support)	25	23%
4	Client advocacy	24	22%
5	Housing assistance/related services	18	17%
6	Food/meals	15	14%
7	Dental care	14	13%
8	Legal assistance	13	10%
9	Mental health therapy/counseling	11	9%
10	Referral	10	8%

South King County clients expressed dissatisfaction with the quality of service provided through DSHS. Several of them described lengthy waiting times for services, lack of professionalism on the part of providers and failure to be given explanations as to why benefits were delayed or denied. Participants were also concerned about tighter eligibility requirements being placed on emergency grants from Lifelong AIDS Alliance, but acknowledged that the reasons for these restrictions were valid.

Service gaps in alternative therapies, peer counseling/emotional support and dental care were each related to the scarcity of available programs outside of central Seattle. Both of the major HIV-related alternative care providers are located in Seattle. Although one provider has begun to sub-contract for naturopathy and acupuncture through East and South County clinics, none of the focus group participants were aware that this option existed. Group support programs are also offered almost exclusively in Seattle, and peer one-on-one support options are limited based on volunteer availability in outlying areas of the county. It should be noted, however, that attempts to offer HIV-focused support groups outside of Seattle have met with minimal attendance, due in part to client concerns about anonymity and confidentiality in their home communities. Focus group participants also noted that while dental care is available throughout the county, there

**continues to be a shortage of dental providers outside of Seattle who are knowledgeable about HIV/AIDS dental manifestations and/or willing to accept medical coupons.**

“I have three options: I can drive myself, which isn’t good because of parking and my car is usually falling to pieces. The second option is to take the bus, which isn’t always wonderful when you are going to the doctor and it also requires three buses and lots of logistics planning. The third option, which is no longer works very well, was [volunteer] transportation services. There are a lot of volunteers on the other side of the lake, but it is hard to get volunteers on this side. The last time, it was just a bad experience.” (Male PLWH, East King County)

Focus group participants also expressed dissatisfaction with the availability of ancillary support services, such as food/meal programs, transportation and volunteer home chore. Consumers pointed to a lack of available volunteers to provide these services, which they attributed to disinterest among non-Seattle residents rather than to agency inaction in recruitment. While most of the focus group participants own cars and drive themselves to appointments, they acknowledged that transportation can be problematic when they are not feeling well. Bus service outside of Seattle is infrequent except during business hours and the routes are often lengthy and time-consuming.

Comparisons between gaps identified by East and South County consumers in 2001 and those identified in 1999 reveal that gaps in most categories have decreased. In particular, the gap identified in alternative, non-Western therapies has dropped from 41% of non-Seattle PWLH to 26% and the gap in financial assistance has decreased from 39% to 29%. Although these figures suggest that several needed services are not as available to non-Seattle PLWH as would be optimal, recent efforts to overcome these discrepancies seem to have been somewhat successful.

## **5. Access Barriers**

As with other consumer sub-populations, East and South King County consumer survey respondents identified a lack of information about available services and an inability to afford needed services as their main access barriers (Table 43). As previously noted, financial barriers were especially pressing for consumers whose income and/or assets did not qualify them for Ryan White-funded services or other government programs, but who could not afford out-of-pocket service fees. Information about HIV-related services is not as readily accessible outside of central Seattle, where the large majority of service agencies are located. As a result, consumers can become highly dependent on case managers to help them learn of and access services when needed.

*“I do wish there could be emergency money to keep auto bills paid, for independence. Living in South King County, there’s nothing in the way of support groups or heterosexual contact groups between Seattle and Tacoma.” (Female PLWH, South King County)*

**Table 43. Access Barriers: East and South County Residents (n=107)**

<b>BARRIER</b>	<b># OF VOTES</b>	<b>% OF RESP.</b>
Lack of information	34	32%

Financial (can't afford it)	18	17%
Geography (live too far away)	12	11%
Service doesn't exist/not available	9	8%
Eligibility (based on financial status)	6	6%

Based on provider interview and consumer focus group response from the 2001 needs assessment, it appears that geographic isolation and lack of non-medical services in non-Seattle King County continue to serve as barriers to service access for this population. PLWH in South and East King County often have to travel long distances to access care in Seattle, prompting some consumers to forego ongoing medical monitoring of their HIV until such time as they are clinically ill.

When asked to comment on ways in which the service system can become more responsive to non-Seattle PLWH, providers suggested that change will not be easy. As several providers noted, many of their clients have chosen to live in South and East County precisely to be apart from the urban Seattle experience. Because the outlying areas of the county are not as densely populated, they will never be as service-enriched as Seattle. They noted that until East and South King County municipalities begin to embrace HIV issues as their issues significant change will not occur.

Providers and consumers offered the following suggestions for overcoming access barriers for East and South King County PLWH:

- Improve coordination and communication between Seattle-based providers and providers of services to non-Seattle residents. This includes outreach to primary care providers, dentists, mental health providers, and other social service agencies in East and South County.
- Increase overall community education and awareness regarding HIV/AIDS issues. Target educational and outreach programs to schools, churches and social service organizations.
- Decrease client isolation through the development of informal support services and client networks outside of Seattle. Use satellite social service centers as the focus of client support and services.
- Maintain and/or expand case management presence in South and East Counties. In these geographic areas, the case manager serves as both a liaison and outreach specialist between the Continuum of Care and social and health service providers in the rest of the county.
- Acknowledge the shortcomings of county-wide public transit programs for persons with AIDS and other disabilities. Assign priority status to the development of new transportation initiatives, both public and volunteer, which can address these issues.

## **F. Homeless Persons**

“Please remember that all of us who have HIV were once tax-paying, voting, working persons. It’s only by the grace of God that this isn’t you.” (Homeless female PLWH)

## 1. Epidemiologic Profile

Although there have been no local population-based surveys of HIV infection in the homeless population in King County, studies indicate that homeless men and women are at high risk for HIV. Homeless people reported with AIDS in King County were more likely to be persons of color and to have been exposed through injection drug use compared to those who were not homeless.

Status and trends in AIDS cases: In King County AIDS case statistics, “homeless” is defined as having no resident zip code at time of AIDS diagnosis. This definition may undercount the number of homeless AIDS cases if, for example, the zip code of a shelter or friend’s home is reported as the zip code of residence, or if the client becomes homeless following diagnosis. Eighty-eight (2%) of the 4,448 AIDS cases diagnosed in King County between January 1991 and December 2000 were reported as homeless at time of diagnosis. During this time frame, 59% of homeless persons diagnosed with AIDS were people of color and 63% were either IDUs or MSM/IDUs, compared to 21% and 16% respectively among persons who were not reported as homeless (Table 44).

**Table 44. Demographic characteristics by homeless status of cumulative King County AIDS cases through 12/00**

	Homeless at time of diagnosis		Not Homeless at time of diagnosis	
	Number	%	Number	%
<b>SEX</b>				
Male	79	(90)	4,202	(94)
Female	9	(10)	246	( 6)
<b>RACE/ETHNICITY</b>				
White	36	(41)	3,494	(79)
Black	34	(39)	484	(11)
Latino/Latina	11	(13)	304	( 7)
Asian/Pacific Islander	0	( 0)	95	( 2)
Am. Indian/AK Native	7	( 8)	71	( 2)
<b>EXPOSURE</b>				
Male/male sex	25	(28)	3,311	(74)
Injection drug use (IDU)	32	(36)	262	( 6)
IDU & male/male sex	24	(27)	428	(10)
Heterosexual contact	1	( 1)	173	( 4)
Undetermined/Other	6	( 7)	255	( 6)
<b>TOTAL CASES</b>	<b>88</b>	<b>(2)</b>	<b>4,448</b>	<b>(98)</b>

Population size: The McKinney Act (Public Health Law 100-628, November 7, 1988) defines homelessness as: “A homeless person is an individual who lacks a fixed, regular, and adequate residence or an individual who has a primary night-time residence that is either (a) a supervised or publicly operated shelter designed to provide temporary or transitional living accommodation or (b) a public or private place not designed for, or ordinarily used as, a regular sleeping accommodation for human beings.” Approximately 5,000 persons are homeless in King County

on any day, of which 500-2,000 are youth/young adults. An estimated 25,000 persons have experienced homelessness in the past year.

HIV seroprevalence: In HIV prevalence surveys conducted by the Centers for Disease Control and Prevention between 1989-1992 of health clinics serving the homeless in ten different cities, the median seroprevalence was 3.3%. In 1998, AIDS Housing of Washington analyzed the results of more than 5,650 surveys of PLWH conducted in twelve regions around the country between 1994-1998. Seven percent of all respondents reported that they were living on the streets, in a shelter, or in a residential hotel/motel at the time they completed the survey, and 41% of respondents had been homeless at some point in time.

## **2. Service Trends**

*(NOTE: Due to difficulty in obtaining survey responses from consumers who were currently without a residence, the needs assessment survey asked consumers if they were currently homeless (without a permanent residence) or had been homeless during the past twelve months. In this manner, it was anticipated that the survey would capture data from individuals for whom homelessness was a historical, as well as current, problem. Of the 538 survey respondents, 58 (11%) reported homelessness within the past year.)*

Consistent with the 1999 needs assessment, providers of services to homeless adults with HIV reported that their client caseloads are largely male, although increasing numbers of homeless female PLWH have been observed in the past two years. On the 2001 consumer survey, homeless respondents were twice as likely than non-homeless respondents to be female (26% versus 13%).

Providers noted that it was very difficult to determine the mode of HIV transmission for many of their homeless clients, due to multiple sexual and substance use risk factors. MSM sexual activity continues to be fairly common among the men, although many do not identify as gay or bisexual. This is particularly true for the growing number of African-American homeless PLWH. Trading of sex for money, drugs or shelter contributes to high-risk behaviors among both men and women in this population. Homeless survey respondents were over three times more likely than non-homeless respondents to report IDU or MSM/IDU history (35% versus 10%).

Consistent with epidemiological trends, over half of the homeless clients that providers reported seeing are persons of color. This includes increasing numbers during the past two years from all non-Caucasian populations. Persons of color were also over-represented among the consumer survey population, with 26% of homeless respondents being African-American, 19% Latino/ Latina, 7% American Indian and 3% Asian/Pacific Islander. Only 41% of the homeless survey respondents identified as Caucasian, as opposed to 74% of non-homeless respondents. As first observed in 1995, providers continue to see increasing numbers of homeless clients who are new to King County. The large majority of these new arrivals are English speakers, but providers did note a slight increase in the number of Spanish speaking homeless PLWH who are now seeking services. Providers also noted that they are seeing an increase in homeless clients who have re-located from downtown Seattle to other points outside the central core of Seattle.

Multi-drug use is also increasing among homeless PLWH, with some providers estimating that as many as 80% of their homeless clients are current or former substance users. Respondents to the consumer survey who stated that they had experienced homelessness during the past year were almost four times more likely than other consumers to report histories of injection

drug use (22% versus 6%). Most clients are alcohol abusers, with increasing numbers of homeless PLWH reporting heroin, crystal meth, and cocaine use.

Although providers noted that their clients are more willing to enter treatment than in the past, access to treatment remains difficult due to long waiting lists, complicated assessment processes, increased paperwork, and fewer detox beds. For most clients, adherence to substance use treatment goes hand-in-hand with housing stability. If the client is released from in-patient treatment back to the streets, the odds of relapse increase dramatically.

Mental illness diagnoses have historically been high among this population and continue to increase. Providers noted that the majority of their clients have been diagnosed with clinical depression. They also report an increase in the clients they are seeing who have Axis II conditions (personality disorders), as well as large numbers of clients with Axis I diagnoses (bipolar disorder, schizophrenia or organic disorders). Homeless survey respondents were significantly more likely than other PLWH to report having been diagnosed with a mental illness (43% versus 29%). As with substance use treatment, providers noted a connection between housing and mental health status. In many cases, the clients' mental illness remains undiagnosed until successful housing is secured.

Many homeless PLWH also have histories of incarceration. Providers report that over half of their homeless clients have spent some time in jail or prison, with most crimes being drug related. The number of clients who are entering the HIV/AIDS care system immediately upon release from jail is increasing. Survey respondents who reported being homeless were significantly more likely than other consumers to report having been in jail or prison during the previous year (22% versus 5%).

Providers reported seeing homeless clients across the entire spectrum of HIV disease. Some of the homeless clients they first encounter have been HIV+ for a long while and have received no care for their illness. Many of these individuals have high viral loads and low T-cell counts, and first present when their illness is fairly advanced. Homeless survey respondents were significantly more likely than other PLWH to be HIV+ non-AIDS, (62% versus 34%), and less likely to have been AIDS diagnosed. However, the number of homeless PLWH who are now receiving AIDS diagnoses is increasing, according to providers.

Homeless PLWH are slightly less likely than other PLWH to be using antiviral medications, protease inhibitors and medications to treat or prevent opportunistic infection. However, homeless PLWH were significantly more likely to report having adherence problems related to their medical regimens (41% to 29%). Providers noted that access to prescription drugs is not a major problem for their clients, but other lifestyle factors (e.g., substance use, mental illness) make adherence to HAART therapy extremely difficult. As a result, doctors and their homeless PLWH clients may often agree not to begin HAART therapy until some level of housing stability has been established.

**Although 91% of homeless PLWH respondents to the consumer survey reported currently receiving primary care for their HIV infection, this is probably an overestimate based on targeted sampling of homeless persons currently in the care system. It is probable that many homeless PLWH who are HIV infected are unaware of their serostatus, and are not currently receiving primary care or other support services.**

**Once homeless PLWH become connected to the care service system, either through the efforts of outreach case managers or placement in transitional or permanent housing,**

service utilization rates are comparable to non-homeless PLWH. In fact, 2001 homeless survey respondents reported service utilization rates that were fairly similar to those of non-homeless PLWH. In several categories, homeless respondents reported higher rates of utilization, such as food and meals (60% versus 46%) and transportation services (41% versus 31%), while in other key service areas homeless PLWH reported lower utilization rates: dental care (62% versus 72%) and client advocacy (72% versus 85%).

### 3. Service Priorities

Consumer survey respondents who reported themselves as currently homeless (or homeless within the past year) listed housing assistance and housing related services as their highest priority (Table 45). Other services that were ranked among the top five highest priorities were case management, dental care, primary medical care and emergency financial assistance.

Homeless consumers were significantly more likely to prioritize housing assistance than other PLWH (69% versus 45%). The need for affordable, safe housing programs is obviously a high priority for most homeless individuals, particularly for homeless men and women living with HIV. Participants in the homeless PLWH focus group expressed concern that living in shelter situations as a person with HIV is extremely difficult. They relayed experiences of being ostracized by other shelter residents, victimization and violence, and lack of privacy and confidentiality in taking medications. Several consumers also spoke of overt discrimination they experienced at the hands of shelter staff who did not want HIV+ individuals in their facilities. However, for persons who have not lived in stable housing situations for a long period of time, the transition into permanent housing can be difficult without readily accessible support services. Providers emphasized the need to develop housing services that provide on-site access to substance use treatment, mental health counseling, and medication management.

*“When I came to this clinic, I had only been here for four days in this city. And I told my case manager my situation, that I’d been homeless and how sick I was getting at the shelter because of all the different things coming through there. He gave me a number to a hotel that’s like a program. And he did really great for the housing.” (Homeless female PLWH)*

Both consumers and providers of services to homeless PLWH stressed the importance of case management. Because many homeless PLWH enter the HIV/AIDS care system with little or no knowledge of available services, dependence on case managers for information, referrals and assistance with service access is quite high. Providers noted that case management has become increasingly important in helping their homeless clients with medication adherence issues. Several participants in the homeless focus group expressed deep gratitude for the ongoing support and assistance provided by their case managers, but noted that case managers seem to be busier and more overworked than in previous years.

**Table 45. Service Priorities: Homeless Persons (Current or in past year)  
(n=55; 3 missing responses)**

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Housing assistance/related services	38	69%
2	Case management	30	55%
3	Dental care	29	53%



4	Ambulatory/outpatient medical care	26	47%
5	Direct emergency financial assistance	23	42%
6	Food/meals	22	40%
7	Client advocacy	21	38%
8	Insurance programs	18	33%
9	Mental health therapy/counseling	16	29%
10	Substance use treatment/counseling	15	27%

As in previous years, providers of services to homeless PLWH highlighted the importance of substance use treatment as a top priority for their homeless clients. An increasing percentage of homeless consumers are in agreement with this opinion, as the rate of homeless PWLH who prioritized substance use treatment rose from 17% in 1999 to 27% in 2001.

Consumer focus group participants reported that medical care was very easy for them to access, once they decided to seek care. They noted that information about HIV medical care was available to them through homeless programs and through word of mouth among other homeless PLWH. Several consumers stated that “the word on the street” is that private doctors will treat you badly if they perceive you to be substance-using, but their experiences with public clinics proved otherwise. Homeless consumers expressed high levels of satisfaction with the care they had received, particularly in comparison to medical care many of them had received prior to moving to King County.

#### 4. Service Gaps

Current or formerly homeless consumers ranked housing assistance and related services as the service they most frequently needed but could not obtain (Table 46). Housing services were followed by alternative therapies, emergency financial assistance, client advocacy and peer emotional support programs.

**Unlike prior years, homeless PLWH survey respondents identified relatively similar service gaps as other consumers. The sole disparities were observed in the areas of housing assistance (40% of homeless PLWH noting difficulties accessing the service versus 17% of other PLWH), client advocacy (29% versus 18%), and alternative/non-Western therapies (33% versus 21%).**

**Table 46. Service Gaps: Homeless Persons (Current or in past year)  
(n=58)**

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Housing assistance/related services	23	40%
2	Alternative, non-Western therapies	19	33%
3	Direct emergency financial assistance	18	31%
4	Client advocacy	17	29%
5	Counseling (emotional support)	15	26%
7 (tie)	Mental health therapy/counseling	10	17%
7 (tie)	Referral	10	17%
9 (tie)	Legal assistance	9	16%
9 (tie)	Dental care	9	16%
11 (tie)	Food/meals	7	12%
11 (tie)	Transportation	7	12%

*“I plan to move to wherever I can afford to. I can’t afford to stay here in Seattle. I mean, it’s stupid of me to stay here and be homeless for years when I can move [to another part of Washington State] and have an apartment just like that. But what are my choices? Stay here? Stay homeless?” (Homeless female PLWH)*

Lack of housing remains the greatest single barrier for homeless PLWH in their efforts to obtain or maintain continuity of HIV care and supportive services. The lack of permanent, safe housing compromises clients’ health due to unsanitary conditions, the threat of physical violence, and lack of privacy in dealing with personal health concerns. Transient living arrangements also complicate provider/client follow-up. These problems are exacerbated by the high rates of mental illness in the population.

Persons with criminal histories and/or current substance use issues face even greater challenges in obtaining housing. Focus group participants expressed a desire for “second chance” housing for persons with criminal records, particularly if the record is more than five years old. They

suggested that housing providers need to look at criminal records with time consideration (so as not to penalize people based on older convictions) as well as the severity of the offense

A further complication was noted by homeless focus group participants in 2001: the majority of the current HIV-specific housing units are located in downtown Seattle, the area of the EMA with the highest concentration of substance-using individuals and access to street drugs. Living in downtown Seattle may serve to subvert the efforts of homeless consumers who are striving to come to terms with their substance addictions. However, accepting housing choices in other parts of the county poses problems in accessing medical care and other needed services.

Unfortunately, the 2001 Report on HIV/AIDS Housing in Seattle-King County (prepared by AIDS Housing of Washington) suggests that King County continues to experience an affordable housing crisis. Although the number of available new housing units has increased by 13% from 1998 to 2000, the supply has not kept pace with the increasing need, resulting in increased demand by low and very low-income individuals and families with fixed or diminishing incomes. The situation is complicated for persons seeking HIV/AIDS housing, because average rents throughout most of the county exceed the fair market rents allowed by HUD (the federal Department of Housing and Urban Development). The estimated need for rental subsidies among people living with AIDS far exceeds federal HOPWA (Housing Opportunities for People with AIDS) funding for the entire EMA.

Until permanent or transitional housing can be provided, accessible food, nutrition and personal health care services are also necessary, but difficult to access. As in previous years, providers suggested combining meal programs with other social services, both as an incentive to attract clients and as a means to provide meals to persons in need. However, providers noted that the majority of homeless programs and shelters in King County are not capable of addressing the specific health care needs of their HIV infected clients.

Participants in the homeless PLWH focus group also reported a lack of peer advocacy and support programs. This is particularly true for homeless PLWH who have yet to connect with the HIV care system, and are not receiving medical care or do not have a case manager. They wanted to be able to share knowledge and information with other PLWH who have had similar experiences in safe, confidential settings. Several focus group members noted that it is very difficult – and dangerous – to mobilize against drug dealing and criminal behavior “on the street” or in residential settings for fear of violent reprisals.

## **5. Access Barriers**

As with other consumer populations, homeless PLWH survey respondents identified lack of information about available services as the main barrier to accessing services in King County. (Table 47). This knowledge deficit is particularly problematic for clients who are recent arrivals to Seattle and those with severe mental health problems. As noted previously, access to effective case management becomes vital for these consumers in learning about the Continuum of Care and in helping them enroll in and follow through with services.

Focus group participants stated that homelessness itself is the greatest of all potential access barriers. Fulfilling basic needs, such as obtaining food, maintaining personal hygiene and

finding safe shelter, take precedence over medical and social service appointments. Both consumers and providers also noted that the perceived stigma attached to being homeless (or living in service-enriched housing) can also be a barrier for clients who seek other services.

Providers noted several ongoing barriers that impede homeless PLWH from obtaining housing. These include current and former substance abuse histories, mental illness, lack of housing or rental history and criminal records. In some cases, clients may minimize their substance use history or fail to disclose their current substance use in order to receive services. For those who are actively using, drug-seeking can become the “job for the day”, as noted by one focus group participant, and medical and social service appointments may be ignored. Even for those clients who do acknowledge readiness to enter treatment, availability of in-patient detoxification beds continues to be limited and waiting lists continue to be lengthy.

*“We became homeless this year because we could no longer work and we had a very expensive house payment. It was nice. We were used to living that way. And we could have gotten housing real quick separately. They would have paid up to \$800 a month separately to house us. But it’s really hard to convince them to pay \$900 a month for us to live together. Now isn’t that stupid? It seems there is a glitch in the rules somewhere.” (Homeless gay male PLWH with partner)*

**Table 47. Access Barriers: Homeless Persons (Current or in past year)  
(n=58)**

BARRIER	# OF VOTES	% OF RESP.
Lack of information	20	34%
Financial (can’t afford it)	10	17%
Waiting list; not enough services	6	10%
Geography (live too far away)	5	9%
Service doesn’t exist; not available	3	5%

The ability of many homeless persons to cope effectively with HIV is further compromised by mental illness. This can complicate care at all levels: initial access, follow-through with appointments and ongoing treatment compliance. Skilled mental health professionals are vital in working with this population, particularly as the number of homeless clients who present with severe mental illness continues to grow.

Providers noted that lack of transportation, especially to medical appointments, is increasingly an access barrier for their homeless clients. This reflects the movement of clients out of the downtown core to other Seattle neighborhoods and the inherent transportation challenges associated with this.

Service providers and homeless consumers suggested several solutions for overcoming access barriers. These include:

- Educate the HIV/AIDS provider community about the realities of homelessness and mental health issues. Ensure that HIV service agencies feel welcoming to clients who are currently homeless or living in service-enriched facilities for formerly homeless persons.
- Educate the mental health, substance use and shelter provider systems about HIV issues. Work on developing increased sensitivity among these providers to HIV issues and increased capacity to make appropriate referrals into the HIV system.
- Expand the system of outreach to homeless individuals to improve case-finding and linkages to care services. In order for homeless persons to feel comfortable entering the HIV system (or any system), ongoing relationships must be developed and nurtured between outreach staff and clients.
- Improve collaboration and accountability between the HIV/AIDS, mental health, substance use treatment and housing systems. Although gains have been made in recent years, communication between these systems can still be difficult. Service providers in each system must take responsibility for optimal care of all clients, and not “hand off” homeless PLWH to providers in other arenas without ongoing follow-up and monitoring.
- Explore alternative housing options for persons with criminal histories. Although this population is extremely difficult to house, it may be possible to pilot transitional housing programs directed expressly to formerly incarcerated persons to improve their chances of successful permanent housing placement.

## G. Youth and Young Adults (Ages 14-24)

*“When I got tested, I didn’t get the results for a year due to thinking they would be positive. I lived in denial until I figured out I was ready to accept the news. I had an “It figures” attitude as opposed to “Why me?” I really wanted the person giving me my results to be a friend. The person did the best she could, but it was just a doctor at the clinic.” (Young adult female PLWH)*

### 1. Epidemiologic Profile

HIV infection does not appear to be widespread among the general King County adolescent population, although it is present. Young men who have sex with other men (MSM) are disproportionately affected compared to other youth, and are at the greatest risk of HIV infection. Teenagers reported with HIV or AIDS through 12/00 are more likely to be African American and more likely to be female compared to older PLWH.

Status and trends in AIDS cases: From 1982 through December 2000, 6,096 AIDS cases were diagnosed in King County. Of these, 12 (<1%) were in persons 14-19 years old and 151 (2%) in persons between the ages of 20-24. As of December 2000, an additional 1,340 King County residents with non-AIDS HIV infection were diagnosed and reported. Of these, 43 (3%) were 14-19 and 170 (13%) fell between the ages of 20-24.

HIV seroprevalence: The estimated number of King County residents ages 14-19 with HIV is between 75 and 110 (midpoint=95). No estimates were available specific to the population of young adults between the ages of 20-24. Anonymous HIV prevalence surveys have been conducted in several specific populations in King County. Recent studies of HIV infection in youth and young adults reveal a variety of seroprevalence data (Table 48).

**Table 48. Seroprevalence In Youth/Young Adults from Various King County Surveys**

SOURCE OF DATA	AGE (YRS.)	HIV+/NO. TESTED	% HIV+
AIDS Prevention Program, 1996-2000	<20	27/1,122	2.4
AIDS Prevention Program, 1996-2000	20-24	282/4,413	6.4
STD Clinic, 1996-1999	<20	0/483	0.0
STD Clinic, 1996-1999	20-29	14/2,783	0.5
Young Men’s Survey, 1997-1998	15-18	0/85	0.0
Young Men’s Survey, 1997-1998	19-22	5/201	2.5
Young Men’s Survey, 1998-2000	23-29	22/462	4.7
Selected Drug Treatment Facilities, 1997-1999	<25	2/127	1.6

Important sub-group – Young gay males: Over two-thirds of the AIDS cases diagnosed between ages 13 and 24 were in males who had sex with other males (with or without injection drug use), 8% were non-MSM injection drug users, 9% had heterosexual risk, and 10% had no identified risk.

Results from risk behavior surveys provide important information about behaviors that may place young people at risk for HIV infection. Preliminary results from Public Health's Young Men's Survey show that 53% of MSM ages 15-18 and 64% of 19-22 year olds who had had anal sex in the past six months did not use a condom. The 1999 Seattle Public Schools Teen Health Risk Survey showed that 40% of high school students had had sex. Of those reporting sex in the previous three months, 61% had had sex without a condom at least once during that time.

## **2. Service Trends**

Providers report that the demographic trends first observed among their adolescent clients in the late '90's continue: an increase in female clients, clients of color and increasing co-morbidity rates (chemical dependency and mental health issues). Providers now report that the majority of their young adult clients are female. Many of the young women have children, are pregnant, or are contemplating having children. This is consistent with data from the consumer survey that indicate that 68% of youth/young adult respondents are female, as opposed to 12% of respondents aged 25 and older.

Providers of services to youth/young adult PLWH describe their client population as predominantly unemployed, with most living at or below the poverty level. Young adult respondents on the consumer survey were significantly more likely than older consumers to report incomes under 100% of federal poverty level (58% versus 39%). Most of these young adult clients are receiving DSHS assistance. Many of the young PLWH are living in unstable living situations (on the street, in shelters, or in short-term arrangements with friends). The population of street-identified youth includes a high percentage of transient adolescents, who have little or no employment history and may not be integrated into the social and health care delivery system in the area.

Providers also noted that their young adult clients are more likely than other clients to reside outside the city of Seattle. Young adult survey respondents were almost twice as likely to report non-Seattle zip codes as older consumers, with 16% residing in East King County (versus 6% of older consumers) and 21% in South King County (versus 14%).

The population of youth/young adult PLWH is more racially diverse than the population of older PLWH. Although their caseloads are primarily white, providers noted growing numbers of African-Americans (and immigrant Africans), and increasing numbers of Latino clients. On the 2001 consumer survey, only 32% of PLWH between the ages of 13-24 identified as white, with 37% identifying as Latino and 21% as African-American. In contrast, 73% of older survey respondents identified as white, with 27% identifying as persons of color.

Due to the low numbers of HIV-infected adolescents in the EMA, the small number of responses from 13-24 year olds on the 2001 consumer survey (n=19) was not surprising. As a result, it is difficult to effectively quantify specific service needs of this population. However, of this sample population, 94% stated that they are currently receiving primary care for their HIV. A significantly higher percentage of 14-24 year old respondents noted that they were HIV+ and asymptomatic than did older PLWH (68% versus 29%). It is therefore not surprising that the percent of young PLWH taking prescription medication was much lower than for older PLWH

(47% of young adults taking antivirals and 21% taking protease inhibitors, versus 80% and 54% respectively for older PLWH). Providers reported that less than half of their young adult clients are on HAART therapy, and that adherence rates are relatively low even among those clients who have decided to begin combination therapy.

According to focus group participants and provider reports, access to the spectrum of medical, pharmaceutical and ancillary services is not a significant problem for their young adult clients. A large majority of HIV-infected youth/young adults who know their serostatus are connected with and are receiving medical care. Most of these clients are experiencing few, if any, health problems related to their HIV status. Providers reported that there is very little HIV-related morbidity in this population.

Utilization of case management services is very high among young adults with HIV, particularly for young women. Seventy-four percent of 14-24 year old PLWH reported using case management services on the 2001 survey. Case managers for young PLWH report that their clients are extremely dependent on them for service access and require that the case manager initiate contact with almost all other services.

Although providers report that mental health issues and multi-drug substance use are high in this population, low percentages of youth/young adult survey respondents report utilization of mental health or substance use services. Only 16% of young adult survey respondents stated that they are using substance use treatment services, and 37% reported using mental health counseling. Clients tell their case managers that they are willing to accept referrals to these services, but rarely follow through after the initial visit. Despite the low rate of follow-through, providers stated that they are seeing incremental change in the percent of young clients who are willing to accept mental health services. They also noted that providers of mental health care have become more accessible and willing to work with young adult PLWH in recent years.

Drug and alcohol use continues to be widespread in the population. Providers reported that almost all of their young adult clients have some history of substance use, ranging from recreational drug use to heroin addiction. Pregnancy has been the key factor in encouraging young female PLWH to enter substance use treatment; results for young males entering treatment have been mixed.

### **3. Service Priorities**

Unlike prior years, young adult consumers identified service priorities that were relatively similar to those identified by older PLWH. Dental care emerged as the top service priority for this population, followed by case management, primary medical care, insurance programs and housing assistance (Table 49). Providers of services to young adult PLWH were in agreement about these priorities. In particular, they stressed the importance of providing targeted case management services to this population. Without ongoing, highly involved case managers, most of the young adult PLWH would fail to connect with the HIV service system.

*“I know I wouldn’t have the knowledge and skills to get by on my own if my case manager was no longer available. It’s so helpful to have your case manager do the*



*looking and searching for you. Once I found out I was positive, I just didn't feel like doing anything but now I have my case manager there to do it.” (Young adult male PLWH)*

Focus group participants echoed the importance of case management. The participants noted that their case manager not only assisted them in finding out about services, but also frequently accompanied them to appointments, was available for emotional support, and acted as both a friend and mentor.

**Table 49. Service Priorities: Youth and Young Adults (Age 14-24)  
(n=19; 0 missing cases)**

RANK	SERVICE	# OF VOTES	% OF RESP.
1	Dental care	13	68%
2	Case management	12	63%
3 (tie)	Ambulatory/outpatient medical care	11	58%
3 (tie)	Insurance programs	11	58%
3 (tie)	Housing assistance/related services	11	58%
6	Client advocacy	9	47%
7	Drug prescription program (ADAP)	7	37%
8	Mental health therapy/counseling	6	32%
9 (tie)	Direct emergency financial assistance	4	21%
9 (tie)	Food/meals	4	21%
9 (tie)	Counseling (emotional support)	4	21%

#### **4. Service Gaps**

Young adult respondents to the consumer survey identified gaps in a wide range of services. The most frequently cited gaps were alternative therapies, client advocacy, housing assistance, and food and meal programs (Table 50).

Young adult focus group participants noted difficulty in obtaining access to non-Western medical care. Several of the youths expressed distrust of the traditional medical care system, and favor alternative care over Western medical care. They noted that it is difficult for them to afford this type of care, and were upset by what they perceived as an anti-naturopathic bias on the part of their primary care providers.

*“I feel overwhelmed by my condition, but I have hope about the medications. I am worried about being discriminated against or abused.”” (Young adult homeless female PLWH)*

Lack of housing has been and remains a major problem for youth and young adult PLWH. Due to their age, lack of rental history and reliable incomes, most youth cannot qualify for housing

programs. Additionally, because most young adult PLWH are not yet AIDS-disabled, they do not meet eligibility requirements for placement in most AIDS housing facilities. As a result, many of the youth continue to live in unstable family situations, on the street, in shelters, or “couch surfing” with friends. Providers noted that, for this population, housing stability is directly tied to medical access. Getting their young adult clients to maintain access to health care was described as “almost impossible” in the absence of stable living situations.

**Table 50. Service Gaps: Youth and Young Adults (Age 14-24)  
(n=19)**

<b>RANK</b>	<b>SERVICE</b>	<b># OF VOTES</b>	<b>% OF RESP.</b>
1	Alternative, non-Western therapies	7	37%
2 (tie)	Client advocacy	6	32%
2 (tie)	Housing assistance/related services	6	32%
2 (tie)	Food/meals	6	32%
5 (tie)	Referral	5	26%
5 (tie)	Treatment adherence support	5	26%
5 (tie)	Mental health therapy/counseling	5	26%
8 (tie)	Dental care	4	21%
8 (tie)	Insurance programs	4	21%
10	Direct emergency financial assistance	3	16%

Lack of access to food and meal programs emerged as a major service gap, identified by both consumers and providers. Young adult survey respondents were over three times more likely than older adults to identify gaps in this service (32% versus 9%). This is particularly true for young PLWH who lack permanent housing and cannot get home-delivered meals, or those who live outside central Seattle and do not have easy access to grocery pick-up programs.

Two services that were significantly more likely to be identified as gaps by young adult PLWH than older consumers were referral resources (26% versus 9%) and treatment adherence support (26% versus 4%). In general, young focus group participants were unaware that referrals to medical and dental care providers were available from the AIDS Care Access Project. As noted by providers, medication adherence is a major issue among this population, most of whom do not have the same kind peer support available to sustain their medication compliance as older consumers do.

Although access to primary medical care per se was not identified as a service gap, providers and focus group participants noted that discomfort in standard medical care settings was fairly common among young adult PLWH. Hospital clinic settings were described as “unfriendly” and “scary” for adolescent PLWH, most of whom are unfamiliar with the medical care system. Providers noted that teen and young adult clinics are needed to provide a welcoming, non-threatening environment for their young adult clients.

## 5. Access Barriers

Age was identified as the main access barrier for youth and young adult PLWH by providers and focus group participants. Although focus group participants stated that could access almost all services when needed, they expressed discomfort in accessing services which they feel are targeted to adults in their 30's-40's. They did note that the situation has improved for young adult PLWH in the past few years, but that communication between providers and young adult PLWH still needs to be improved.

*“The perfect thing would be to have someone there a lot who knows everything that will happen. I’d love for someone to be able to come to my house for any question that would come up. A person to call on at all times.” (Young adult male PLWH)*

As with other populations, lack of information emerged as the main access barrier identified by young adult survey respondents (Table 51). As noted previously, young adult focus group participants were often unaware of the services available in the Continuum of Care, and were highly dependent on their case managers to help them access services.

**Table 51. Access Barriers: Youth and Young Adults (ages 14-24)  
(n=19)**

BARRIER	# OF VOTES	% OF RESP.
Lack of information	6	32%
Financial (can’t afford it)	4	21%
Waiting list; not enough services	2	11%
Conflicts with schedule	2	11%
Haven’t asked	2	11%
Eligibility (based on disability status)	2	11%

Providers noted that general life chaos served as a barrier to accessing services for the majority of their young adult clients. Most of the young adult consumers have unstable home environments, with few caring adults available to help them navigate the medical and social services systems. As noted by one provider, “Remembering [appointments] is tough, due to homelessness and chaotic lives. Medical care is just not a priority for youth.”

Financial constraints can also serve as a barrier. As noted previously, the large majority of young PLWH have little or no personal income. Money management skills in this population are virtually non-existent, according to providers. As a result, what little money these clients do have is spent either on necessities (such as food, rent, and clothing), recreational activities, or drugs. There is rarely money left over for co-pays for medical or other clinical care.

Providers and consumers offered several suggestions about how to improve service delivery and access for youth and young adult PLWH:

- Increase and maintain access to youth-focused case management. Acknowledge that effective case management for this population is labor- and time-intensive, and requires extensive outreach.
- Youth service providers must be prepared to focus on support and advocacy for their clients within the broader service system. This involves creating ongoing, intensive linkages with other service providers to ensure that client needs are expressed and understood.
- Develop a comprehensive system of care for youth and young adults. The more different agencies a young person has to deal with, the greater the likelihood that s/he will fall through the cracks. Providers of individual services, particularly medical care, need to realize that compartmentalizing service delivery will not work for this population.
- Demonstrate flexibility in working with young adult PLWH. The client might be difficult to locate, appointments might be missed and communication might be inconsistent and frustrating. Trust takes time to build, and only through building trust will young clients maintain access to the system.